“HIDING AND SEEKING”

Health problems and problems in accessing health care of undocumented female immigrants in the Netherlands

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Chapter 1

Introduction

GENERAL INTRODUCTION

"I swear by Apollo the healer, Asclepius, Hygieia and Panacea and I take to witness all the gods, all the goddesses, to keep according to my ability and my judgment, the following Oath and agreement……"

The right to health care is a human right recognized by the UN international covenant on Economic, Social and Cultural rights.[1] States are under the obligation to provide equal access to preventive, curative and palliative health services for all persons, including undocumented immigrants.[2] In theory this may be true but in practice undocumented immigrants cannot always claim this right. Undocumented immigrants have a marginalized position in our society. They cannot speak up for themselves. Since they have no permission to stay in the host country and live in permanent fear of being reported to the authorities, they will not easily report complaints and problems they experienced when claiming their right to health care.

Undocumented women are supposed to be even more marginalized. Since they often live in dependence of male partners or employers it is even more difficult for them to speak up. In order to guarantee the right to health care, undocumented women should be given a clear and loud voice. That is the main relevance of our study.

A woman without residence permit in the consultation room

Saida L, 30 years, makes her first visit to a General Practitioner (GP) since she became "undocumented" in the Netherlands. Nine years before she arrived in the country after an arranged marriage. Saida's country of origin is M, were she grew up in a small traditional village in the mountains. Because of her marriage with a legal resident, she obtained a residence permit. Already in the first month of her marriage she was forced into prostitution by her spouse. She was unable to speak Dutch or English and was kept in captivity by her husband.

After 2 years she gave birth to a girl. She escaped with her daughter from her husband after she was forced again into prostitution shortly after the delivery. Unfortunately this occurred one month before she would have obtained a permanent residence permit. Saida became "illegal".

Saida is without residence permit for 7 years now. After her escape she received shelter for short periods from different friends or acquaintances. Sometimes she had to stay a few days on the street. She was continuously afraid to be arrested by the police. She did not consider going back to M., because of her divorce. She would become a social outcast in her village without income and respectability. Saida perceives her health as poor. She experiences several health problems. She is tired and listless for some years already. She suffers daily from headaches. Yet her most important concerns are about the health and development of her daughter.

Since two weeks Saida suffers from increasing lower abdominal pains. Intercourse is painful and she notices that her vaginal discharge changed colour.

HEALTH STATUS

There are approximately 75,000-185,000 immigrants without legal status living in the Netherlands; 25,000-50,000 of them female.[3] This population constitutes one of the most excluded and vulnerable social groups in our society. They lack good housing and working conditions, live in poverty, isolation and in the permanent threat of being arrested by the police. Furthermore they have experienced difficult circumstances in their country of origin: war, violence, famine, poverty, natural disasters and human rights violations. Women in this category are even more vulnerable in their position of dependency of male persons (marriage, family reunion, wife of a political refugee, human trafficking) and to gender based violence in particular.[4] It is reasonable to expect that these conditions have a negative effect on their health status.

On the other hand some studies show that recently migrated legal immigrants report better health in comparison to the regular host country population.[5-7] This phenomenon, known as the "healthy migrant effect", is attributed to the various selection processes that immigrants undergo before arriving at their destination. Since most people go to another country expecting to work, those who migrate are most frequently the fittest and best able to survive the journey. For undocumented immigrants this might apply even more strongly as the journey without documents and the expected living conditions as undocumented in the host country are even tougher than for legal immigrants.[8] We are curious if this assumption is correct and if this presumed better health continues if people have to live as an illegal resident in the Netherlands. Legal immigrants rate their health worse than autochthonous people in the Netherlands[9] and both physical and mental health problems are highly prevalent among asylum seekers and refugees.[10]

Studies among undocumented women are scarce and include only women that have been able to make contact with health services or welfare support services.[11-18] We found no information about the health status and health problems of the "invisible" women who are not in contact with health care facilities. Furthermore, in most studies data on health and health problems of undocumented immigrants were obtained from health care professionals and not directly from undocumented women themselves. These studies provide information about health problems of undocumented immigrants presented to the doctor, not about all the health problems perceived by the women. Hidden problems, e.g. vaginal discharge can certainly influence health status and are therefore important to register.

So, research based information on the health status and the specific health problems of undocumented women is lacking. For clinicians it is important to have this information in order to provide adequate care. Therefore we decided to

explore the health status and specific health problems of undocumented women in the Netherlands.

SEXUAL AND REPRODUCTIVE HEALTH

Problems with sexual and reproductive health often have serious consequences for the wellbeing and health of women and their families. The definition of health by the WHO implies for reproductive health that people are able to have a responsible, satisfying and safe sex life and the freedom to decide if, when and how often to reproduce.[19] According to article 12 of the United Nations international bill of rights for women, states shall ensure to women appropriate services in connection with family planning, pregnancy, confinement and the post-natal period.[20]

On basis of their marginalized position in society we have reason to believe that the sexual and reproductive health status of undocumented women is under pressure. Many women experienced physical assault or sexual violence in their past and live in dependency of men.[20;21]

The Population Action (2007) stated that the Netherlands is one of the safest countries for women's sexual and reproductive health.[22] This does not fully apply to immigrant women in the Netherlands. For example maternal death among asylum seekers is 4 times higher than for autochthonous women.[23] Further there is a rising incidence of abortions, Sexually Transmitted Diseases (STDs) and the risk of maternal death among immigrants.[18;24;25] Female immigrants in other western countries face problems with sexual and reproductive health as well. Refugees in the EU suffer from higher maternal morbidity and mortality, experience inferior pregnancy outcomes,[26-28] have less access to SRH services including family planning and safe abortion services, report higher levels of HIV and other sexually transmitted infections (STIs), and are more likely to become victims of gender-based sexual violence.[21;29] Many

may also suffer from post-traumatic stress disorder due to sexual assault and violence.[30]

We know from studies amongst undocumented immigrants visiting a health facility in Geneva that they were more exposed to violence during pregnancy[14] and that the majority of the pregnancies was unintended.[14;15] All these studies however report results of women that were able to make contact with health facilities. No research based information is available about the sexual and reproductive health of undocumented women in the Netherlands. Therefore, we wish to investigate reproductive and sexual health needs of undocumented women in the Netherlands.

HEALTH CARE UTILISATION

Shortly after her escape from her husband Saida consulted the GP she used to visit when she still lived with her husband. This GP told her that she had to pay cash for the consultation because she was no longer insured. After that she never went back to him again.

In the following 6-7 years she never visited a health care institution again despite several health problems. Friends told her that the doctors might call the police. She managed to obtain medication for her child through faked prescriptions for a child of friends.

Recently she was advised by a friend to approach a voluntary support organization about her housing situation. This organization helped her to find temporary residence in a shelter home. While in this shelter home she developed increasing abdominal pains. After a few days volunteers from the shelter home arranged an appointment for her with a GP.

In the Netherlands, all regular residents are obliged to accept health insurance, but in 1998 a new law prohibits undocumented immigrants to obtain this insurance.[31] Simultaneously the Dutch government aims at equal access to

health care.[32] Undocumented immigrants are entitled to receive all "medically necessary care", that should be defined as responsible and appropriate medical care as indicated by the treating doctor,[32] whether or not they are able to bear the costs of the medical treatment themselves. During our study, before January 2009, a special fund reimbursed health care providers if the undocumented immigrant was insolvent. GP's, midwives and pharmacists could obtain a 100% reimbursement. Hospitals and mental care institutions were initially obliged to cover unmet costs out of their own resources. Today, reimbursement for general practice is available for up to 80% of the costs. Reimbursement for hospital care is now also possible. However, the reimbursement of hospital care and pharmaceutical care are restricted to designated institutions. Costs for pregnancy care are fully covered.[33]

Although access to health care is guaranteed in theory, no information is available what the effect of these legislations is in practice. Health seeking behaviour and access to health care are influenced by more and other factors than legal and financial.[34-36] In several publications, researchers, professionals and organizations expressed concern about the accessibility of health care services for undocumented immigrants in western countries.[14;15;37-57] These publications mention limited or short entitlements, complicated administrative procedures, discrimination by and ignorance of health care workers, lack of information and financial means and permanent fear of being denounced. Only one publication regarding Spain, where in 2002 legal changes provided access to free medical care for undocumented immigrants in similar terms as the Spanish population, concluded that there was no difference in access to health facilities between documented and undocumented persons.[58]

The vast majority of the publications are opinion papers, overviews, commentaries or editorials.[38;39;42;44;48;50-53;55;57;59] There were some studies that indicated obstacles in accessing care by interviewing health care professionals or relevant representatives in the field.[41;43;47;49;54] In only three studies

undocumented immigrants were interviewed in person.[14;15;37] The studies that interviewed undocumented immigrants in person included only persons that had been able to make contact with health care institutions or support organizations. At the time of this study we only knew of one study in the United States that also included undocumented immigrants that could not make contact with health care institutions.[56] Apart from a few studies concerning antenatal care,[12;14-16] we found no studies about general health care utilization and the problems in accessing care for undocumented women.

Because of the insufficient information about the actual use of health care facilities by undocumented women and about obstacles they experience in accessing health care, we decided to explore these subjects with inclusion of women that are not known by health care professionals or voluntary support organizations.

PATIENT-HELD RECORDS

Saida followed a Dutch language class in the past 5 years, but communication is still difficult. Saida feels a sense of shame to seek help for her gynaecological symptoms. She mentions abdominal pain to the GP but she conceals abnormal discharge and painful intercourse.

The GP notices a large scar on the abdominal skin. Saida explains that she had surgery 8 years ago in Amsterdam, but she cannot explain the reason why. Medical record information is not available. The GP feels uncertain and decides to refer her for an ultrasound and laboratory tests.

Physicians experience serious problems to provide undocumented immigrants with proper care as a result of communication problems, complexity of morbidity and extra workload.[38;60] Furthermore lack of adequate medical record information is a problem. Undocumented immigrants visit different physicians at different places and are often not registered on a permanent basis. Therefore,

past and actual record information are often not available.[61] As a consequence continuity of care for undocumented immigrants is critical. This probably influences the quality and costs of care.[62;63] Knowledge of a patient's medical history is a substantial contributor in saving time, referrals and reduction of the use of medication.[64] Moreover it improves health outcomes.[65] In the Netherlands nearly all inhabitants are registered with a GP; the GP administers all first line care, functions as a gatekeeper to specialist care and coordinates other health services when needed. Also undocumented immigrants are supposed to visit a GP for health care problems. Lacking medical record information therefore is a problem in particular for GP's.

A computer-based record system is in most cases not feasible for undocumented immigrants since they frequently change residence. Further, the confidentiality of personal and medical information pertaining individuals in this group is of paramount importance.

In theory, patient-held records might be a solution for this problem and can be valuable for many physicians all over the world. A patient-held medical record (PHR) will probably enhance the continuity of care as well as the empowerment of patients. In the Netherlands Médecins du Monde has recently started issuing PHR's for undocumented immigrants. However, the uncertainty of the appropriateness of a PHR for undocumented immigrants is considerable because studies about the use of PHR by undocumented immigrants are lacking. Therefore we wish to investigate the suitability of a patient-held record for undocumented immigrants.

AIMS OF THE THESIS

Against the background as described above the following study aims were formulated:

- To gain insight into the health status of undocumented women in the Netherlands and into the specific somatic and psychosocial health problems they experience.
- To assess which reproductive health problems and needs exist among undocumented immigrant women and explore if they are able to fulfil these needs.
- To explore health care utilization data and obstacles that influence health care utilization of undocumented women.
- To explore the suitability of a patient-held record for undocumented immigrants.

METHODOLOGICAL AND ETHICAL CONSIDERATIONS AND LIMITATIONS

Undocumented patients are very difficult to recruit since they live in permanent threat of being arrested by the police and therefore try to hide. As a consequence the scarce studies that were executed interviewing these persons included only people that have been able to make contact with health care facilities or support organizations. Exploring views and experiences of undocumented women themselves, including the "invisible" women, is necessary to get insight in their health status, healthcare utilization and obstacles in accessing health care. The EU project "Health care in Nowhere land" states that this uncertainty/ignorance and invisibility are in a way functional for sustainability of practice. Conducting research among undocumented immigrants is conducting research in a "vulnerable space". [66;67]

Research amongst undocumented women, especially when including women that are not in contact with health care institutions or support organizations, has methodological consequences. Systematic recruitment through health care institutions, e.g. a GP, as common in health surveys, is not possible. Because undocumented women are nowhere systematically registered, gathering a statistically sound representative sample is not possible. The size of different

groups of undocumented women in the Netherlands can only be estimated.[3] Including undocumented women that are not in contact with health care institutions or voluntary support organizations means that recruitment must take place through unusual channels and requires careful considerations. Recruiting participants in this way is time-consuming and very difficult. Potential participants are afraid for immigration authorities and try to hide. After contact is established their trust should be gained and their safety should be guaranteed.

For this vulnerable population informed consent is particularly important. Because many women are illiterate, afraid and reluctant to sign any paper, the Nijmegen University Ethical Committee allowed us to obtain the necessary informed consent for the study orally. We made a lot of effort to explain the study in two or three different occasions. We did this orally and we used written information that we had available in 8 different languages (Appendix 1). We asked the participants twice if they agreed to participate in the study.

The exploration of patterns of health seeking behaviour, influencing factors and perceived barriers, should preferably be performed by in-depth interviews conducted in the women's own language by somebody of her own culture. Unfortunately, because of the large diversity in origin this approach was not feasible in our study. This has consequences for the richness of the qualitative data.

Because the group of undocumented women consists of women of very different origin and cultural background, systematically measuring health in this group is complicated. Communication problems are common. Standard questionnaires, like SF 36, are not validated in so many languages. In most literature concerning regular immigrants, health status is measured by self-perceived health, chronic conditions and health complaints, sometimes completed with results of a health questionnaire. [5;6;9;10;68] Because this is a valid and feasible manner of measuring health, also among minority populations,[69-76] we decided to measure health status in our study population by perceived health, the number of chronic

conditions and health complaints. Extensive physical examinations are often burdensome and can discourage participation in the study. Therefore we decided to do a rather small physical examination including blood pressure, pulse, length, and weight, global examination of head, neck, chest, abdomen en extremities and HB. Results of the physical examination were mentioned in the PHR. Abnormalities were reported in a letter to the GP.

For several reasons obtaining a direct answer on the question if undocumented women have control over their sexual and reproductive health is very difficult. This requires real in-depth interviews and these are, as we stated before, not feasible in this patient group. Therefore we decided to explore exposure to violence, use of family planning methods and abortion figures as they give an indication of control over their sexual and reproductive health.

Finally, research in this vulnerable group obviously requires careful ethical questions and considerations. Identifying women that were not able to contact health care facilities ensures that the researchers become involved in the participants health seeking behaviour. It is unethical to interview these women about barriers in accessing health care and not help them access this care. Therefore we provided them with a medical advice and assistance in finding a GP.

STUDY DESIGN

We decided to conduct an exploratory study, including undocumented women with a maximum variety in socio demographic factors. Undocumented women ≥ 18 years were purposively recruited through churches, (voluntary) support organisations, General Practitioners (GP's) and midwives. To find women not yet identified by health professionals or an organisation, advertisements were placed in local newspapers and recruiting posters were placed in locations frequented by immigrants. Further we made use of snowball sampling: we asked participants with whom contact had been established to refer us to other females

who could potentially participate. We aimed to interview a group of 100 women, striving for maximal diversity. Diversity was sought according to age, country of origin and reason for being undocumented. After successfully including 80 women in four different cities in the Netherlands, we evaluated the composition of the study population and actively sought for women that were underrepresented in the study population: undocumented labour immigrants and victims of human trafficking.

The undocumented women that showed interest to participate in our study were given an explanatory letter in their own language. If necessary instructed mediators from e.g. support organizations provided oral explanation of the study. If women were interested to participate contact was established with the research assistant. She further clarified the purpose of the study to the women or to a relative. If the women agreed to participate an appointment for an interview was made. The interviews were held in different locations: public and primary health institutions, a shelter home, a nursing home and occasionally in the women's temporary shelter. These locations were kept secret, also for mediators.

To provide a nuanced and comprehensive understanding of the (reproductive) health problems and needs of undocumented female immigrants, their obstacles in accessing health care facilities and the acceptability of a patient held record, we applied different methods; structured interviews, semi-structured interviews and focus group discussions. Both undocumented women and their GP's were interviewed. An overview of the research activities is provided in figure 1.

Between January 2007 and September 2008 one-hundred women were interviewed. The first session consisted of 4 separate parts; first a consultation with the GP about health problems, medical history taking and physical examination, next an interview with the research assistant about health care

Figure 1: Overview of research activities

A. First session with women (jan 2007-sept 2008)

1. Interview with GP: Health status **1 hour**
   - Single- item question on self-rated health
   - Which health problems do you experience at the moment?
   - Standard lists of common health problems, obstetric health problems and chronic conditions
   - History taking and global physical examination

2. Interview with research assistant **1 hour**
   - Socio demographic information
   - Structured questionnaire on health care utilization
   - Semi structured interview regarding obstacles experienced in assessing health care

3. Medical advice and provision of PHR by GP **30 min**
   - Medical advice and provision of PHR

4. Advice by research assistant **30 min**
   - Information about use of PHR
   - Information about Dutch health care system (DVD and Folder)
   - Provision of an address of a suitable GP if necessary

B. Second session with women (3 months later)

1. Follow-up interview with research assistant **30 min**
   - Inspection PHR for new entries
   - Experience and use of the PHR

2. GP's of the women about PHR:
   - Structured Questionnaire by mail: experiences and usage

C. Focus group sessions (3 months later)

1. Focus group discussions with women **1,5 hour**
   - Views and experiences regarding PHR's
2. Focus group discussions with GP's **1,5 hour**
   - Views and experiences regarding PHR's

utilization, followed by provision of a medical advice and the PHR. Finally, the provision of information about the Dutch health care system, the PHR and provision of an address of a GP if women were not yet registered. These parts were handled successively on the same day. This was efficient and resulted in minimal inconvenience for the participants and maximal participation.

In the first part health problems were first assessed by a GP using an open-ended question, "Which health problems do you experience at this moment?" We then provided the participants with a list of common health problems, reproductive problems and obstetric problems and a concise list of chronic diseases. (Appendix 2) General perceptions of health were evaluated through a single item question on self-rated health: 'In general, would you say your health is excellent, very good, good, moderate or bad?' Finally history taking and a concise medical examination including blood pressure, pulse, weight, length, examination of head, chest, abdomen and extremities and HB, took place.

Socio-demographic information was obtained at the start of the second part and included data about country of birth, marital status, children, housing conditions, occupation, education, duration of residence in the Netherlands and reason for staying in the Netherlands. Data about use of health care services were obtained through a structured questionnaire. In order to explore obstacles experienced in accessing health care, semi-structured questions were asked. The interview contained the following themes: reasons for not-using health care facilities and obstacles encountered in accessing facilities.

Preferably the women were interviewed alone in both the first and the second part. However, when a woman insisted on the presence of a partner or a friend, this was not refused. To women that were unable to communicate in English or Dutch interpretation was offered. The participants were informed that their answers would be processed anonymously. Given the fact that it was very difficult to gain the trust of the women since many of them were afraid of being arrested by the police, we did not to audiotape the interviews.

During the third part participants were provided with a PHR and a medical advice by the GP. Medical and personal data were entered in the PHR. The purpose of collecting these data was to favour the women. The PHR used in the study was developed by an expert panel and was designed for adult undocumented immigrants. (Appendix 3) It was designed for use by one individual only. An A5 size, soft, covered booklet in a transparent cover provided space to insert additional leaflets, test results, and appointment cards. It contained separate sections for personal details, medical history, chronic diseases, medications, and allergies. Space was created for free text entries by health professionals, details of earlier pregnancies, results from blood tests, and useful addresses and telephone numbers.

In part four, participants received information about the Dutch health care system through a DVD that we had available in 21 languages. Further they received a folder about the Dutch health care system that we developed for this specific group in 7 languages (Appendix 4) and an address and telephone number of a GP close to their place of residence who was willing to register undocumented patients.

After 3-4 months, the research assistant approached the women again to make an appointment for the second session and asked them to bring the PHR. If after several attempts the research assistant did not succeed in making contact with the participant by telephone or SMS, an invitation was mailed to the last known address. The interview was conducted by the research assistant. Respondents were asked about the use of the PHR and the PHR was checked for new entries. (Appendix 5)

In the same period we mailed the GPs of the women a questionnaire that required minimal time to complete in order to ensure a satisfactory response. Questions concerned the use of and experience with the PHR. simultaneously focus groups were conducted by independent moderators to enable in-depth exploration of the attitudes towards the PHR and enhance an exchange of

opinions. All women participating in the study that understood and spoke Dutch sufficiently were invited to attend these focus group discussions. GPs practising in Nijmegen and Rotterdam that had at least five contacts with undocumented immigrants in one year were invited to attend one of the special focus group for GPs.

RESEARCH QUESTIONS

With consideration to the methodological limitations of research in this population we formulated four research questions and investigated these.

1. How do undocumented women perceive their health? Which health problems do they report?
2. Which reproductive and sexual health problems and needs do undocumented women experience? What obstacles do undocumented women experience when they try to fulfil these needs?
3. What is the use of different health care facilities by undocumented women and which barriers in access to health care do they perceive?
4. What is the use and acceptability of a PHR for undocumented immigrants and GP's?

OUTLINE OF THE THESIS

The research questions are answered in chapter 3-8. **Chapter 2** provides extensive background information on living circumstances of undocumented immigrants, demographic data, legislations on access to healthcare in different Western countries and human rights. Further demographic details and results of the physical examination of our research group are presented. In **Chapter 3** research question 1 is answered. It describes the perceived health and the specific health problems of undocumented women. General perceptions of health were evaluated through a single item question on self-rated health: "In

general is your health excellent, very good, good, moderate or bad?" Health problems were assessed by an open-ended question" Which health problems do you experience at the moment" and by a list of common health problems and chronic conditions. Not all data we collected on health status are described in this thesis. A summary of these data is provided in appendix 7. In **Chapter 4** research question 2 is answered**.** We explore reproductive and sexual health problems of undocumented women. We used a structured questionnaire. **Chapter 5** is part of research question 3 in which we report about the limited access to facilities where TB can be diagnosed and treated. In **Chapter 6** research question 3 is answered. This chapter describes the use of health services by undocumented women and the obstacles they experience in accessing health care. We used structured questionnaires and semi-structured interviews. To answer research question 4 we first carried out in **Chapter 7** a systematic literature review related to the potential benefits of a patient-held record (PHR) for undocumented immigrants. In **Chapter 8** we describe the appropriateness of a patient-held record for undocumented immigrants in General Practice. We used structured interviews about the use of a PHR with undocumented women and General Practitioners (GP's), and we performed focus group discussions with undocumented women and focus group discussions with GP's. Finally, in **Chapter 9** we present an overall discussion and conclusion.

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Chapter 2

Undocumented immigrants. Who are they? What are their health rights?

Undocumented women are a generally unnoticed and neglected group in our society. From a state perspective undocumented migration shouldn't exists. Undocumented immigrants themselves try to hide; they live in permanent fear of being reported to the authorities. As a consequence we do not know much about them. We want to investigate the health status and access to health care of undocumented women. However for a correct interpretation and understanding of their health problems and their health seeking behaviour, we need to get to know them better. We need to know about their origin and past and the legislations they are subject to. We provide applicable background information in this chapter.

TERMINOLOGY

There are several terms in use for non-citizens that are residing in a country, without official permission to do so: e.g. illegal immigrants, unauthorized immigrants, undocumented immigrants or irregular immigrants. The reasons for existence of different terms are diverse: some have a historical background, some reflect anti-migration sentiments, others pro-migration attitudes.[1]

The term illegal immigrant is often criticized.[2] Immigrants can never be illegal in their existence as a person, only their activities can be regarded as such. On the other side this term most clearly defines the group and the explicit role of legislation.[1] However, because of the association with crime of the term "illegal", several authors and organizations use terms like undocumented immigrant, unauthorized immigrant or irregular immigrant. [3-8] Also these terms can be confusing. The term 'undocumented' can be confusing because many immigrants who have no permission to reside in a country do have identification documents. Also, not all illegal immigrants are 'unauthorized' e.g. when application for regularization is pending. The term 'irregular' is problematic as well since it can also be understood as disorderly, which again has a criminal association. Further it is also described as immigration that takes place at

irregular time intervals. Finally, all terms do not explicitly define the legal position of a person.

Unfortunately there is no objective and commonly accepted term. We choose to use the term "undocumented" as it is most commonly accepted and recommended by PICUM despite its disadvantages.

DEMOGRAPHIC BACKGROUND

United Nations estimate that 3 percent of the world's population (213 million in 2010) live outside their country of origin.[9] Most immigrants move from underdeveloped to developed countries, where immigrants constitute more than 10 percent of the population. Understandably no exact numbers of un-documented immigrants in the world exist. Given the fact that large numbers of these individuals live in hiding for authorities, it is obvious that exact numbers are impossible to determine. Estimates suggest that there may be 30 million undocumented immigrants worldwide. It is estimated that undocumented immigrants make up 4 percent of the population of the USA.[10] Estimates for European countries are lower: 1 to 2% of the total population, except for some Mediterranean countries, such as Greece, where the percentage is higher (3.4%).[11] For more than 40 years, female immigrants have been almost as numerous as male immigrants.[12]

In the Netherlands, with a population of 16 million people, estimations range between 75.000-185.000 immigrants without legal status, 25.000-50.000 of them female.[13] In estimations for the Netherlands data regarding persons arrested by the immigration authorities and labour inspectorate are used.[13;14] In the Netherlands the vast majority of the estimated undocumented population is male. The method used for the estimations might play a role is this. Presumably women are less likely to get arrested so their figures may be significantly higher in reality.

The demographic background of undocumented immigrants differs between Western countries. Whereas in the US most undocumented immigrants originate from Middle America, undocumented immigrants in Western Europe come from Sub-Saharan Africa, North Africa, South America, Eastern Europe, Asia and the Near or Middle East.[4] Between European countries differences exist in the origin of their undocumented population. Colonial past, language and legal migration history play an important role. In the Netherlands there are relatively large undocumented populations from Surinam, Turkey and Morocco.
Undocumented immigrants in Europe are relatively young.[4;13;14] In the study of van der Heijden in the Netherlands, 80% was younger than 40 years.[13]

REASONS FOR UNDOCUMENTED STAY

There are a number of reasons why women can become an undocumented immigrant. E.g. they may enter a country, apply for asylum but be rejected after legal proceedings and ordered to leave the country, but neglect the order. Or by legally entering a country on a tourist visa or temporary residence permit and overstaying the permitted period of stay. Or even by birth if the parents of the newborn stay without documents in the country.
Reasons for migration can be economic, personal or political. In the Netherlands labour immigrants constitute the largest group. These are persons that came to the Netherlands for economic reasons. They mainly live in the four largest cities: Amsterdam, Rotterdam, Utrecht and the Hague. In this group males aged 20-40 are the larger majority.[14] They originate mainly from Turkey, North-Africa, Surinam and Eastern Europe. The women in this group are even younger and come from South-America, Sub Sahara Africa (mainly Nigeria), Eastern Europe and Asia (mainly China and the Philippines). Frequently women are trafficked and end-up working in the sex industry.[15] Another large group of women works as domestic worker.

A substantial group undocumented women in the Netherlands are refugees. This group is very vulnerable. Among them are many women, often with children, with traumatic experiences in the past and without social network. They are afraid to go back to their country of origin or do not want to go back. For many of them it is even not possible to go back because the country of origin does not accept their return (China, Somalia) or they have no documents of the country of origin.

A third group consists of women, mainly from Turkey, Morocco and Surinam, that came to the Netherlands for personal reasons such as family reunion and marriage. Some of these women can rely on strong social networks, but many are forced into a hidden and secret life after divorce because of fear for reprisals from their family. Among them are also women that lost their residence permit after divorce from a husband with legal status in the Netherlands. Defence for Children estimates that there are 30,000 thousand undocumented children in the Netherlands.[16] Every year 1200-2000 undocumented babies are born.[13]

LIVING CIRCUMSTANCES OF UNDOCUMENTED IMMIGRANTS IN GENERAL

Coming from different countries and cultures undocumented immigrants experienced different circumstances in their country of origin: war, violence, persecution, famine, poverty, natural disasters and human rights violations. Also the journey they undertake to reach the host country is dangerous and strenuous. According to Fortress Europe 14,797 people have perished in attempts to reach Europe over the last 10 years; 10,925 immigrants died in the Mediterranean sea and the Atlantic Ocean towards Spain, and 1691 lost their life trying to cross Sahara desert in order to reach Europe.[17] PICUM's newsletter reported 1479 immigrant deaths at European borders in 2008. [18]

In the host country undocumented immigrants also experience problems. For undocumented immigrants it is extremely difficult to obtain adequate housing. They have a low or unpredictable income, are confronted with abusive practices

by landlords and lack entitlement to social housing. This generally results in poor housing conditions for most undocumented immigrants. In a study of Médecins du Monde less than half of the European undocumented immigrants (46%), had access to permanent housing. Many undocumented immigrants live with family or friends, others rent housing accommodation through private commercial offices.[4;14;19;20] Housing conditions are often unsuitable. Overcrowding, poor sanitary facilities, poor hygiene, absence of warm water, cold and moist conditions are common.[20] These conditions can affect the health status of undocumented immigrants.

Undocumented immigrants usually obtain an income through many different activities at the black market such as domestic work, hairdressing, paint houses, gardening and many other activities.[21] Labour inspectors in the Netherlands found most undocumented workers in the catering industry (mainly Chinese restaurants), construction industry, agriculture, and retail trade.[19] Working conditions are often unfavourable: low wages, long working hours, exploitation and unsafe working conditions. Also these conditions can influence their health status.

The lives of undocumented immigrants are dominated by the fear for deportation. Many avoid going out as much as possible and stay in their accommodations. Most undocumented immigrants in a study in Belgium express the permanent fear as the most painful aspect of their life.[21] They acquire a wealth of *street wisdom*: how to walk, talk, dress or avoid eye contact to escape from the attention of the police or other authorities. Undocumented immigrants express astonishment about the "paper society" they arrived in. They consider documents as a western invention.[21] Many undocumented immigrants were not aware at all that they needed a visa or residence permit. Especially in Africa most people do not own a passport and never need one. Therefore they consider themselves an innocent victim of bureaucracy.

LIVING CIRCUMSTANCES OF FEMALE UNDOCUMENTED IMMIGRANTS

When males migrate in search of jobs, there is usually little pressure that their children will join them.[12] In most cases, men leave their children behind in the care of the mothers. The situation is different when women migrate. Gender roles in most cultures lead to the expectation that women will care for the children. The result is that most mothers that migrate still face the need to care for their children. These women are under pressure to settle quickly in their new places of residence so that they can be joined by their children. Women that migrate from low-income countries often leave their children in the temporary care of other family members and not necessarily with the fathers. This situation further contributes to the pressure to get their children to join them.

Female war refugees usually escape with their children and, because these women are usually the primary caregivers, they have the responsibility to provide food and other essentials to their children, even when they are in a position that does not allow to earn some money.[22] They may neglect their own health problems since the problems of their children have their priority.

Many female undocumented immigrants experienced or experience physical assault or sexual violence.[23;24] The precariousness of the labour market for undocumented female immigrants means that they are more prone to violence and sexual harassment since they depend on their employers to retain their job.[25] Undocumented women are more often victims of human trafficking[24] and also prostitution is common, as sometimes it is the only way to earn some money.[4] This gender-based violence can have serious health consequences, such as STD's and Post Traumatic Stress Syndrome.

On the other side the narrative of victimhood and the assumption that women are forced to migrate and work in prostitution, versus the story that men are in control, resulted in protective measures in several countries.[2] For example housing in shelter homes is more easily accessible for female undocumented

immigrants than for men and risk of deportation is smaller. [2;4] Undocumented women are portrayed as victims, men are associated with crime.

HUMAN RIGHTS

Human rights are "rights and freedoms to which all humans are entitled".[26] Proponents of the concept usually assert that everyone is endowed with certain entitlements merely by reason of being human.

The modern conception of human rights developed in the aftermath of the Second World War as a response to the Holocaust, culminated in the signing of the Universal Declaration of Human Rights by the United Nations General Assembly in 1948. However, the intellectual foundations of the concept of human rights can be traced through the history of philosophy and the concepts of natural law rights and liberties as far back as the city states of Classical Greece and the development of Roman law.

The 1948 Universal Declaration on Human Rights contains articles on Civil and political Rights as well as on social and economic rights. Efforts to 'translate' this Declaration into a binding convention took a relatively long time. Finally these rights were codified in two different instruments, one dealing exclusively with civil and political rights (first generation rights) and one on social, economic and cultural rights.[27] First generation rights, like freedom of expression and freedom of religion are classical civil and political rights, where the state has to refrain from interfering. The second generation human rights such as right to health, the right to education and the right to a fair trial cannot easily achieved by individuals. Active involvement of the state is required by setting up for example proper education, health care and juridical systems.

Both first and second generation human rights apply to all people, including undocumented citizens. The right to health is a second generation human right recognized by the UN international covenant on Economic, Social and Cultural rights.[28] The right to health is related to other human rights. For example human

rights violations adversely affect health.[27] The WHO states that *the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition.* States are under the obligation to provide equal access to preventive, curative and palliative health services for all persons. [29] The right to health is secured in a different way and with different methods in the different counties according to their traditions. But all have to provide the necessary standard which is consistent with the human right to protection of health.

For women, the implication of the definition of health by the WHO regarding reproductive health is equally important. The WHO states that individuals should be able to have a responsible, satisfying and safe sex life and the freedom to decide if, when and how often to reproduce.[30] According to art 12 of the United Nations international bill of rights for women, states shall ensure to women appropriate services in connection with family planning, pregnancy, confinement and the post-natal period. By their ratification of this bill, states are obliged to grant free services when needed as well as access to health care services.[23]

Medical professionals who give care to undocumented immigrants have to cope with contradictory demands. The European Project "health care in Nowhere land" describes this paradox.[31;32] If medical professionals provide care, they may act against legal and financial regulations; if they do not, they do not only violate human rights and the Hippocratic oath by excluding the most vulnerable, but they also violate professional guidelines and legislations. There are various guidelines according to which doctors are bound to apply their knowledge and skills to improve the health and well being of the patient, to offer qualitative care- whilst respecting the patients right to self-determination- and to act in the interest of public health.[33;34] Doctors must treat patients equally in equal

situations and may not accept any orders conflicting with generally accepted medical-ethical opinions.

LEGISLATION CONCERNING HEALTH CARE IN DIFFERENT WESTERN COUNTIES

Numerous international instruments in human rights, that refer to the right of everyone to health care, are ratified by European Union member states, the United States and Canada. Yet, laws and practices in many countries deviate from these obligations.[35] However, laws and regulations are heterogeneous.[1;3;4;6-8;36-42] Some countries are highly restrictive and entitle undocumented immigrants to almost no rights or on a payment basis only and others are more generous.

In some countries immigrants (e.g. Spain and Portugal) are entitled to access practically all types of preventive and curative care. However, in these countries the administrative steps to access health care are often complicated.

In other countries such as France and Germany there are restrictions to enjoy free of charge medical care, e.g. minimum duration of residence in the country or a defined lack of resources. Also here, procedures to comply with these conditions are complicated.

In the United states medical treatment provided to undocumented immigrants is only covered under Medicaid for immunizations, treatment of communicable diseases and 'emergency medical conditions'.[39]

In most countries "emergency care" is guaranteed. The vagueness of this term however has lead to divergent interpretations by the courts, generating unpredictability and inequity.

E.g. in Sweden, Austria and Greece undocumented immigrants, including children and pregnant women, do not even have access to any emergency care.

LEGISLATION CONCERNING ACCESS TO HEALTH CARE IN THE NETHERLANDS.

In the Netherlands, all regular residents are obliged to accept health insurance, but in 1998 a new law made it impossible for undocumented immigrants to

obtain this coverage.[43] However, they are entitled to receive all "medically necessary care", that should be defined as responsible and appropriate medical care as indicated by the treating doctor,[33] whether or not they are able to pay for their treatment.

Before January 2009, GPs, midwives, and pharmacists received full reimbursement for unmet costs from a special fund if an undocumented immigrant was insolvent; hospitals received reimbursement by means of so-called 'dubious debtors' provisions. Hospitals had to negotiate with health insurance companies about compensation for bills of insolvent patients that remained unpaid. Mental care institutions and nursing homes had almost no possibilities to get reimbursement.

In January 2009, the policy and financial coverage for costs of medical treatment for undocumented immigrants changed. Since then, reimbursement of secondary care is also possible, although restricted to designated institutions; reimbursement for primary care costs is now possible for 80% of the costs. Important for women is that costs for pregnancy care remained fully covered and treatment for pregnancy-related problems is under certain conditions also possible in non-designated hospitals.[44] Professional ethical standards prohibit doctors in the Netherlands reporting undocumented immigrants to immigration authorities.

Living conditions of undocumented female immigrants are precarious. This may have serious health implications. Unfortunately there is no research based information on the specific health problems of this group.[45] Several organizations, like the World Medical Association and COST expressed the need for this research.[8;41] We believe that more information about the health status of undocumented women is needed to provide them with adequate health care and ensure the right to health.

To ensure the right to health for undocumented women also adequate access to health care is necessary. There is a gap between each country's obligations

under international human rights law and the disparate local implementations in diverse countries. In some countries, like the Netherlands, adequate access to health care seems reasonably guaranteed. However, no information is available what the impact of legislation is in reality. Health care seeking behaviour and access to health care are also influenced by more and other factors than legal and financial.[46-48] The actual access to health care need to be studied urgently.

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Chapter 3

Self-rated health and health problems of undocumented immigrant women in the Netherlands: A descriptive study

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ABSTRACT

In this descriptive study, 100 female undocumented immigrants aged ≥ 18 years were interviewed about their health condition. The objective was to gain insight into the health situation and specific health problems of undocumented women. Sixty-five per cent of these undocumented women rated their health as 'poor' (moderate or bad) and 91 per cent spontaneously mentioned having current health problems. When provided with a list of 26 common health problems, subjects reported on average 11.1 complaints. Gynaecological and psychological complaints were very prevalent, but seldom mentioned spontaneously. Also obstetric problems were numerous. Undocumented women may not present important symptoms to physicians when they encounter them. We conclude that physicians should actively ask about psychological and gynaecological problems in this patient group. Special training on the health problems of undocumented female immigrants for health providers is recommended.

INTRODUCTION

Very little is known about the health problems and health situation of female undocumented immigrants who reside in the developed world. An estimated 75,000–185,000 undocumented immigrants live in the Netherlands, 25,000–50,000 of them are women.[1] These women most likely have health problems related to their origin and to their present situation.[2–5] Health problems encountered most frequently in asylum seekers and immigrants are musculoskeletal disease, depression, and posttraumatic stress disorder, and are non-communicable.[6–11] In 1998, the Netherlands declared it illegal for undocumented immigrants to obtain healthcare insurance.[12] Although they have the right to receive all 'medically necessary care' and some funding is possible,[13] access to healthcare facilities by undocumented immigrants is hampered, as in many western countries.[14–18] Yet, physicians in deprived areas of the big cities regularly encounter care-seeking undocumented immigrants in

their consultation rooms.[19] Studies in the Netherlands, largely of men, report that undocumented immigrants present with psychosocial problems, sexually transmitted diseases, and tuberculosis.[20–22] Unfortunately, only one limited study conducted interviews with undocumented immigrants about their problems.[21] To gain insight into the specific health situation of undocumented women, we interviewed 100 female undocumented immigrants with different backgrounds. Our objectives were to determine how female undocumented immigrants perceive their own health and which health problems they experience.

METHODS

As undocumented women are not registered in the Netherlands, it was difficult to select a representative sample. Therefore, we opted for a descriptive approach and sought 100 undocumented women who were diverse in terms of age, country of origin, and reason for being undocumented to participate in the study. Undocumented women aged ≥ 18 years were recruited through voluntary support organizations, general practitioners (GPs), churches, midwives, recruiting posters, and advertisements in local newspapers. We gave undocumented women, who contacted us to participate in our study, an explanatory letter in their own language. The research assistant contacted all women by telephone to explain the study again to the woman or her relative. If the woman agreed to participate, an appointment was made for an interview.

After successfully enrolling 80 women, we evaluated the composition of the study population to ensure sufficient variation. We then looked for undocumented women who were underrepresented in the study population, according to estimates of the different groups of undocumented women in the Netherlands.[1] The first author, a qualified female GP, interviewed all the women in the Dutch or English. For women unable to speak or understand either language sufficiently, we offered interpretation. The women were informed that their answers would be processed anonymously. We obtained sociodemographic

information, including data about nationality, marital status, children, housing conditions, occupation, and education plus the duration of and reason for the stay in the Netherlands.

Health problems were first assessed by an open-ended question, 'Which health problems do you experience at this moment?'We then provided the participants with a standard list of common health problems and a concise list of chronic diseases. Data about obstetric health problems were obtained through a structured questionnaire. General perceptions of health were evaluated through a single-item question on self-rated health: 'In general, would you say your health is excellent, very good, good, moderate, or bad?' The responses were summarized as either 'good' (excellent, very good, and good) or 'poor' (moderate or bad).

Because we provided them with a medical advice and a patientheld record, we considered the possibility that women with multiple and/or serious medical problems were more likely to participate in our study than women with fewer or minor medical problems. Therefore, 16 undocumented women who attended a free dinner provided by a voluntary support organization and 15 undocumented women from a shelter facility were asked to complete a shortened version of the structured health questionnaire used in the study, including the single-item rating of health. This information was then used to check for the possibility selection bias. We used SPSS for Windows to perform the data analysis (version 16.0, Spss Inc., USA). Two-tailed Pearson chi-square tests were used to examine the relationships of self-rated health to the following sociodemographic variables: age, country of origin, religion, marital status, children, employment status, capability of speaking Dutch, duration of stay in the Netherlands, reason for staying in the Netherlands, and place of residence in the Netherlands. To identify the factors that were independently associated with the health outcomes, we ran multivariate logistic regression analyses by entering all variables that reached P-values <0.2 in univariate analysis.

RESULTS

Of the 100 women participating in the study, 47 lived in rural or semi-urban areas in the south east of the Netherlands (Nijmegen, Rosmalen, and Den Bosch) and 53 in large cities (Amsterdam, Rotterdam, and the Hague).

Subject characteristics

Women from Eastern Europe and sub-Saharan Africa constituted the largest subgroups. Most women had come to the Netherlands for political reasons (Table 1). Sixty-three per cent of the women spoke sufficient Dutch or English to participate in the interviews without an interpreter. We used an official interpreter for 13 women and a family member interpreted for 24 others.

Self-rated health

Sixty-five per cent of the undocumented immigrant women rated their health as 'poor' and 35 per cent as 'good'. Table 2 shows adjusted ORs (odds ratios) for the associations between characteristics of the study population with $P<0.2$ in univariate analysis and self-rated health. Rejected asylum seekers judged their health worse in comparison to participants who came to the Netherlands for other reasons ($P<0.030$). The associations between self-rated health and length of stay in the Netherlands and between self-rated health and age group were not statistically significant after adjustment for other variables.

Of the 31 women who did not fully participate in the study, but filled in the shortened version of the questionnaire, 74 per cent judged their health as 'poor'.

Table 1: Patient characteristics of study population

General characteristics	*Study population (n=100)(%)*
Age (years)[a]	36.4 mean (SD=14.7)
Partner	
Yes	53
No	47
Children	
Yes	73
No	27
Religion	
Christian	62
Muslim	23
Hindu	3
Buddhist	2
No religion	10
Country of origin	
Eastern Europe/former USSR	30
Sub-Saharan Africa	21
Turkey/Middle East/Northern Africa	12
China/Mongolia	12
Afghanistan/Iran	11
Middle and South America/Philippines	8
Surinam	6
Reason to come to the Netherlands	
Political reasons	58
Non-political reasons:	42
Economic reasons	14
Personal reasons	29
Employment status	
Unemployed	79
Student	1
Full-time or part-time job	20

(Table 1 continued)

General characteristics	*Study population (n=100)(%)*
Housing	
Semi-permanent residence	24
Temporary residence	69
Homeless	7
Literacy	
Able to read and write	81
Difficulties with reading and writing	8
Illiterate	11
Exposure to violence	
Experienced physical violence	43
Experienced sexual violence	28
Female genital mutilation	3
Involuntary prostitution	5
Mean duration of residence in the Netherlands	7 years (SD=3.7)
Mean duration of residence without documents	5 years (SD=2.8)

[a]One woman did not know her age

Self-reported actual health problems

Ninety-two per cent of the women reported having health problems based on responses to the question 'Which health problems do you experience at this moment?' They mentioned in total 309 health problems; an average of 3.1 complaints per woman. Headache, joint pain, backache, sleeping problems, and lower abdominal pains were reported most frequently. Provided with the standard list, all 100 women reported health problems. Compared to spontaneously mentioned health problems, participants more frequently reported the complaints on a standard list of 26 common health problems (Table 3). Presented with a list of 26, women identified 11.1 complaints on average. Some complaints that were infrequently mentioned spontaneously, such as psychosocial and gynaecological problems, were strongly prevalent.

Table 2: self-rated health: Univariate analysis and logistic regression

Characteristics	*Number (%), 'good' health*	*Number (%) 'poor' health*	*Unadjusted P-value*	*Adjusted OR (95% CI)*	*Adjusted P-value*
General study population	35 (35)	65 (65)	NA	-	NA
Age group			0.007		0.078
18-25 years (26)	16 (66)	10 (34)		1.00	
26-35 years (34)	11 (32)	23 (67)		3.96(1.08-14.47)	0.038*
36-45 years (19)	4 (21)	15 (79)		6.10(1.29-28.91)	0.023*
>45 year (21)	4 (19)	17 (81)		5.28(1.05-26.48)	0.043*
Children			0.094		0.688
Yes	22 (30	51 (73)		1.00	
No	13 (48)	14 (52)		0.79(0.26-2.45)	
Reason for stay in the Netherlands			0.007		0.030*
Political reasons	14 (24)	43 (76)		1.00	
Other reasons	21 (50)	21 (50)		3.30(1.13-9.68)	
Length of stay in the Netherlands			0.033		0.611
<12 months	5 (83)	1 (17)		1.00	
13-36 months	6 (50)	6 (50)		5.27(0.32-87.59)	0.246
37-60 months	7 (33)	14 (67)		6.21(0.40-95.67)	0.190
>61 months	17 (28)	44 (72)		5.82(0.43-79.16)	0.688

Each variable has been adjusted for all other variables in the table. OR, odds ratio; CI, confidence interval; NA, not applicable. *P<0.05.

Table 3: prevalence of common health problems in study population

Complaint	*% Spontaneously reported*	*% When specifically asked for*
Fatigue	4	82
Headache	30	75
Back ache	14	65
Joint pain	18	Not asked for
Dizziness	4	60*
Dental problems	5	51
Palpitations	4	45
Abdominal pain	3	42
Skin problems	10	41*
Weight loss	0	37
Breathlessness	2	35*
Chest pain	8	29
Poor vision	9	28
Cough	3	21
Hearing Loss	0	13
Blood spitting	1	2
Urinary problems (including incontinence)	9	29
Gynaecological problems		
Lower abdominal pain/genital organs pain	11	42
Menstrual problems[a]	10	20
Vaginal discharge	5	23
Sexual problems[b]	2	20**
Vaginal itching	1	17
Psychological problems		
Anxiety	7	78
Sleeplessness	14	75
Agitation	1	71
Depressed mood	9	64
Nightmares	0	53

[a]Question non-applicable for 28 women: menopause or pregnant.

[b]Question non-applicable for 30 women: no sexual contact

*One woman could not answer this question

**Two women did not answer this question

Finally, a few spontaneously mentioned health concerns, such as concern about having 'something gynaecological' (7), concern about having HIV (1), concern about having cancer (2), and concerns about the health of their children (7), were not in our standard list.

Chronic conditions

Hypertension, anaemia, and diabetes mellitus were the most frequently reported chronic conditions (Table 4).

Table 4: Self-reported chronic conditions (n=100)

Chronic condition	*%*
Hypertension	14
Anaemia (not pregnancy related)	8
Hepatitis B/C	3
Diabetes mellitus	6
Asthma	3
Cardiac disease	3
Cancer	2
Epilepsy	0
HIV infection	0

Obstetric problems

Nine women were pregnant at the time of the interview. Twenty-seven women had been pregnant during the period of their undocumented status (abortions not included), two women had been pregnant twice and one three times. Thirty-nine per cent (12) of the women who had been pregnant during their undocumented status reported problems during pregnancy and 59 per cent (12) reported problems with the delivery or neonate (Table 5).

Table 5: Self-reported obstetric problems in 27 undocumented women

	Pregnancies (n=31) (%)
Risk factors or problems of pregnancy:	10 (32)[a]
Hepatitis B carrier	2 (6)
Hypertension/toxemia	2 (6)
Cretinism	1 (3)
Kidney problems	1 (3)
Depression/PTSS	3 (10)
Cervix insufficiency	1 (3)
Thallasaemia	1 (3)
Complications delivery/neonatal problems (n=22[b])	9 (41)[c]
Preterm delivery	2 (9)
Caesarean section	2 (9)
Prolonged labour	1 (5)
Gemelli	1 (5)
Missed labour, multiple handicapped foetus	1 (5)
Low birth weight <2500 g	3 914)
Embryoma spine neonates	1 (5)
Foetal distress	1 (5)
Birth trauma	1 (50)

[a]One woman had two risk factors
[b]Nine women were still pregnant during the interview
[c]Four women had two complications

DISCUSSION

This descriptive study is the first large-scale study in Europe investigating self-rated health and self-reported health problems of undocumented women. The results show that undocumented women report substantially more health problems (11.2) compared to legal migrant women provided with a similar list of common complaints in the Dutch survey of general practice (6.7).[23,24] In particular, psychosocial and gynaecological problems were very prevalent, but

seldom mentioned spontaneously. A history of sexual violence might account for this. [25,26] Undocumented women rate their health as very poor; especially in the subgroup of rejected asylum seekers. Multiple studies, conducted in various cultures and settings, showed that persons reporting poorer self-rated health suffer a higher risk of subsequent morbidity and mortality.[27–30] Although comparisons should be undertaken with care as age, ethnicity, culture, and socioeconomic status all influence self-rated health and because different kinds of rating scales were used,[31–35] there is evidence that the undocumented women in our study rate their health as less good than legal migrant women.[24,36,37] In the second Dutch National Survey of General Practice, 45 per cent of female legal migrants judged their health as 'moderate', 'poor', or 'very poor' (average Dutch population 19 per cent), which is significantly lower than the 65 per cent of our study population.

Length of stay in the Netherlands did not influence the health perception. This may be due to the low number of participants. In Canada, immigrants who arrived relatively recently in the host country judged their health better than those who were residents for a longer period.[36,38] Poor access to health care, long-lasting stress factors, and insecurity may lead to worsening of health status over time. In contrast to acute health problems, which were more frequent, chronic conditions were reported in similar numbers as in legal migrant populations.[24,36] Diabetes was reported more frequently in our study population, asthma, cancer, and heart disease less frequently. The number of pregnant women in this study was too small to draw valid conclusions about pregnancy-related and obstetric problems, although these were numerous. This is in accordance with other studies in the United states and Belgium where undocumented immigrants had elevated risks of labour complications,[39] a higher risk of preeclampsia, 40 and of foetal distress.[39,41]

The most important limitation of our descriptive study is that we lacked a statistically valid, representative sample of undocumented women. Therefore,

conclusions should be drawn cautiously. Bias may have been introduced by the method used for recruiting the sample, as rejected asylum seekers may be overrepresented. We believe that self-rated health may have been rated worse than it is in reality for the total group. Our data, however, do clearly emphasize the vulnerability of this specific group. The sample size in this study was too small to assess influences of important confounding factors, such as ethnicity, literacy, and religion. A large-scale study among this group is, however, impractical. Undocumented women are difficult to recruit, as they live permanently under the threat of being arrested by the police. They try to hide. We managed to recruit 100 women, to gain their trust and guarantee their safety. Therefore, this modest study is unique and contributes much needed information about this vulnerable population. The gap between spontaneously reported health problems and problems reported when prompted specifically is important for daily medical practice. Undocumented women may fail to present important symptoms and problems spontaneously to their physicians. Physicians should therefore actively and specifically enquire about psychological and gynaecological symptoms. Special attention is required for pregnant undocumented immigrants, because their health situation makes them particularly vulnerable. We recommend special training on the health problems of undocumented (female) immigrant patients for physicians.

Policy makers should also pay attention to the health problems of undocumented women. Clearly, most undocumented women perceive their health as moderate or poor and report many health problems. States should guarantee adequate access to health care, removing obstacles services, which should be identified in further studies.

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Chapter 4

Illegal female immigrants in The Netherlands have unmet needs in sexual and reproductive health

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ABSTRACT

Objectives To determine the reproductive health problems of illegal female immigrants and what obstacles they experience when seeking help for these problems.

Methods One hundred illegal female immigrants in The Netherlands aged more than 18 years were provided with a structured list of common reproductive and sexual health problems. Further semi-structured interviews were conducted regarding their experiences with reproductive health facilities.

Results Obstacles accessing reproductive health facilities were frequently reported. Illegal female immigrants were not able to exercise control over their own reproductive and sexual health. The reasons for obstacles accessing reproductive health facilities include lack of information about reproductive health services and contraception, problems with paying for services, sexual and physical violence and fear of deportation. Obstacles accessing reproductive health facilities resulted in lacking or delayed pregnancy care (19% never received antenatal care), infrequent use of contraception and high abortion rates (64.9/1000). Of all interviewed women, 70% reported gynaecologic or sexual problems, and 28% reported past exposure to sexual violence.

Conclusions The reproductive health status of illegal female immigrants in The Netherlands is worrisome. There is an urgent need to empower illegal women through education. The Dutch government should make efforts to improve access to reproductive health and family planning services.

INTRODUCTION

Illegal female immigrants are in a vulnerable position in Western societies. The reasons they live as illegal immigrants differ, yet living conditions are difficult for all illegal female immigrants. Similar difficulties apply to males; however, females are subject to additional problems and increased vulnerability. Many women have experience physical assault or sexual violence in their past and live with dependency on men.[1,2]

An estimated 25,000-50,000 illegal female immigrants live in The Netherlands.[3] It is reasonable to expect that illegal female immigrants have problems with their reproductive and sexual health. The definition of reproductive health by the WHO implies that people are able to have a responsible, satisfying and safe sex life and the freedom to decide if, when and how often to reproduce.[4] According to article 12 of the United Nations International Bill of Rights for Women, states shall ensure women have access to appropriate services in connection with family planning, pregnancy, confinement and the postnatal period. By ratification of this bill, states are obliged to grant free access to health care services.[2] Nevertheless, in many Western countries, access to reproductive health and family planning services is inadequate for illegal female immigrants.[5,6]

All regular residents in The Netherlands are obliged to accept health insurance covering a standard package of essential health care. Illegal immigrants have no right to obtain health insurance, but are entitled to receive 'medically necessary care,' which is defined as responsible and appropriate medical care, as indicated by the treating doctor.[7] At the time of this study (2006-2008), General Practitioners (GP)s, midwives and pharmacists received full reimbursement for unmet costs from a special fund if an illegal immigrant was insolvent; hospitals received reimbursement by means of so-called 'dubious debtors' provisions. Hospitals had to negotiate with health insurance companies about compensation for bills of insolvent patients that remained unpaid. Unfortunately, many

migrants and professionals are unaware of these provisions. The obligation of professional confidentiality in The Netherlands prohibits doctors from reporting illegal immigrants to immigration authorities.

It is questionable if undocumented women in The Netherlands are able to exercise control over their sexual and reproductive life; we wished to investigate this. We are interested in particular in the 'invisible' women, the group that is too afraid to seek care from a doctor. Executing research in this patient group is difficult. Statistically valid sampling is not feasible, since these women are not registered. Furthermore, eligible women are difficult to recruit since they stay in hiding.

We identified a few studies about prenatal care among illegal female immigrants, which were conducted in health care facilities.[8-11] Unfortunately, this setting automatically introduces a selection bias; thus, no information is obtained about women who did not find their way to the health care facilities. Therefore, we decided to seek these 'invisible' women as well. We intended to interview illegal women about their sexual and reproductive health. Our objectives were to assess which reproductive health problems and needs undocumented immigrant women have and what obstacles they experience when they seek help for these problems.

METHODS

Study design

We opted for an exploratory study with mixed methods. Therefore, a structured questionnaire and a semi-structured interview were used to achieve the best understanding.

This study was part of a larger project to evaluate the health status of undocumented immigrant women and the feasibility of introducing patient-held records for illegal immigrants.[12-14]

Study population

Our aim was to identify 100 illegal female immigrants aged more than 18 years living in different parts of the country for participation in the study. Diversity was sought according to age, country of origin and reason for being illegal in the country. We actively sought illegal women who were underrepresented in the study population according to estimates of the different groups of illegal women in The Netherlands (illegal labour migrants and victims of human trafficking).[3]

We personally contacted a number of different (voluntary) support organisations, migrant organisations, shelter homes, churches, an organization for domestic workers and health professionals. We provided the groups with information about our study and asked them to refer possible participants to us. In order to contact women not known to professionals or organisations, advertisements in local newspapers and recruiting posters were placed. Furthermore, we made use of snowball sampling, i.e., we asked participants with whom contact had been established to refer us to other women who could potentially participate.

Illegal women who showed interest in participating in our study were given an explanatory letter. The research assistant contacted all candidates by telephone. During the telephone call, additional information was provided to the women or a relative. If the prospective candidate agreed to participate in the study, an appointment for an interview was made. Preceding the interview, an informed consent was obtained. We provided all participants with free medical advice and provided access to a GP if needed.

Data collection

We performed semi-structured interviews in primary health care facilities or in the person's temporary shelter between January 2006 and July 2008. The interviewer was the first author, a qualified female GP. The women were preferentially interviewed alone. If possible, the interview was conducted in the

Dutch or English language. When needed, telephonic interpretation was offered. The participants were informed that their answers would be processed anonymously. Given the fact that it was very difficult to gain the trust of the women and many of them were afraid of being arrested by the police, we decided not to audiotape the interviews. Socio-demographic information was obtained at the start of the interview and included data about nationality, marital status, children, housing conditions, occupation, education and the duration of and reason for staying in The Netherlands.

The interviewer followed an interview guide prepared by an expert panel and contained the following themes: experiences with pregnancy care and family planning services; obstacles encountered in accessing pregnancy care and family planning services; information about family planning, abortion and preventive screening and experiences with sexual or physical violence.

Furthermore, we questioned a standard list of reproductive health problems, including obstetric problems, gynaecologic problems, sexual problems, contraception use, sexually transmitted diseases (STDs), STD and cervical cancer screening and abortion.

Data analysis

The quantitative data from the standard lists of reproductive health problems and interviews were analysed using SPSS for Windows (version 16.0; SPSS, Inc., Chicago, IL, USA). Two-tailed Pearson chi-square tests were used to examine the relationships between a reported history of sexual violence and the presence of somebody during the interview. Two authors (M.S. and M.v.d.M.) independently analysed the qualitative data of the interviews. Initially, they read and reread the data to gain insight in the most important themes that emerged. Next, the notes were independently coded and subsequently the researchers defined the most important themes together.

RESULTS

We received 124 telephone numbers of women who were eligible to participate in our study (Figure 1). One hundred women originating from 32 different countries were interviewed; 47 women lived in a semi-rural area in the southeast of The Netherlands (Nijmegen, Den Bosch), and 53 women lived in a large city (Amsterdam, Rotterdam, The Hague).

For the demographics of the participants, see Table 1. The mean age of the women was 36.4 years. Thirty per cent of the women originated from Eastern Europe, the former USSR or Yugoslavia. Twenty-seven per cent of the women had been pregnant during their illegal stay in The Netherlands. Sixty-three per cent of the women spoke sufficient Dutch or English to participate in the interviews without an interpreter. For 13 women, we used a qualified interpreter (8 females and 5 males) and for 24 women, a relative served as an interpreter (15 females and 9 males). Although we preferred to interview the women alone, 50 women came (for practical or security reasons), to the interview accompanied by one or more children (*n=9*), their partner (*n=12*), a volunteer (*n=5*), a female family member or friend (*n=20*), or a male family member or friend (*n=4*). In order not to lose the trust of the women, we permitted these companions to attend the interview.

Pregnancy and pregnancy control

Twenty-seven women were pregnant during the period of their illegal status (abortions not included). For the characteristics of the pregnancies, see Table 2. Two women were twice pregnant during their illegal stay, and one woman was pregnant three times. For those women, the first pregnancy while illegal is included. In the later pregnancies, antenatal visits started earlier (three in the first trimester and one in the last trimester). Nine women were still pregnant at the time of the interview. Two of the women (22%) experienced domestic violence.

Figure 1. Flow diagram of the study

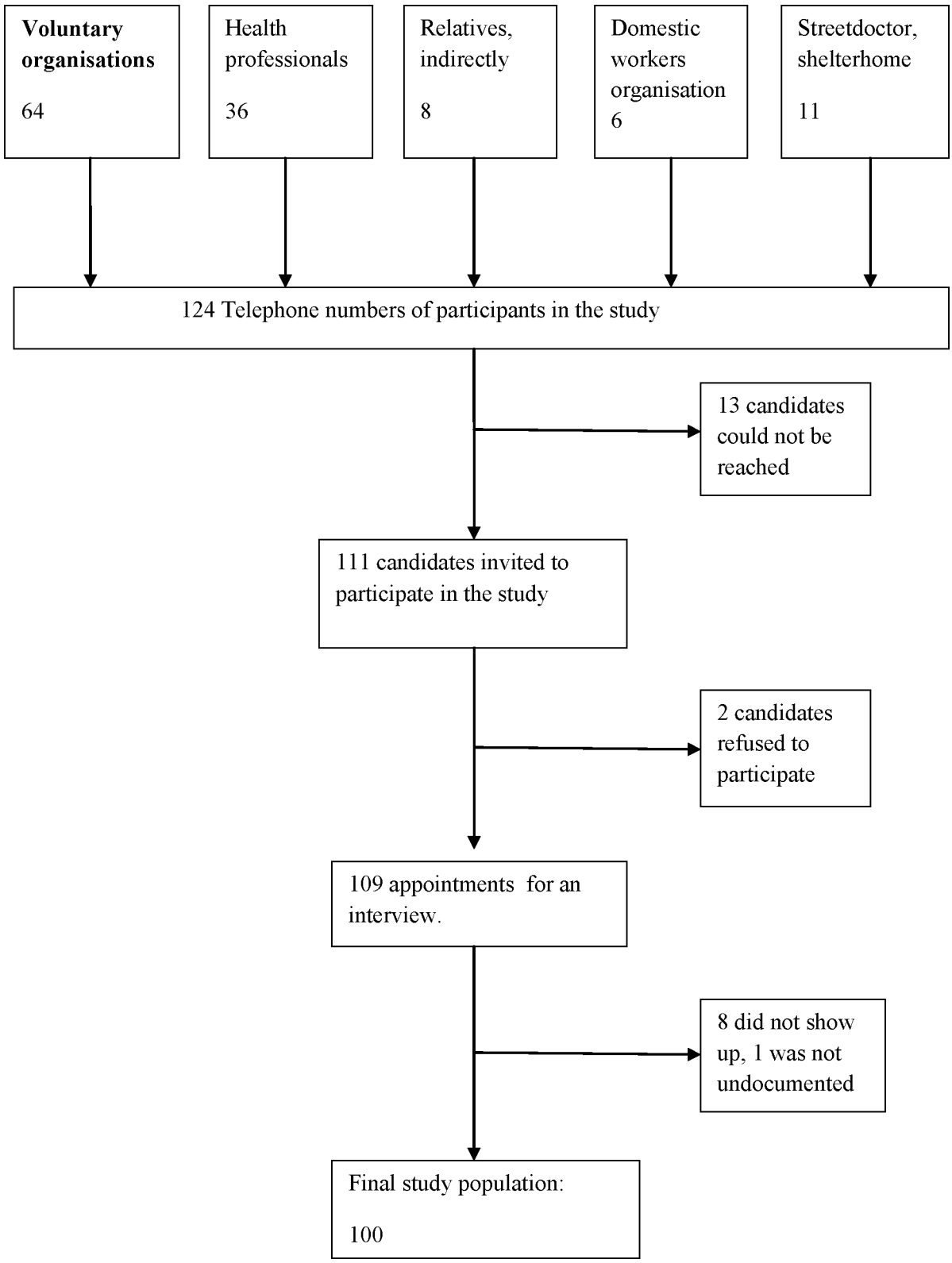

Table 1: Patient characteristics

	(n=100)
Age, years [a] (SD)	36.4 mean (14.7)
Pregnant during interview	9%
Pregnant while illegal	27%
Having children	73%
Partner	53%
Country of origin	
Eastern Europe/former USSR/ Yugoslavia	30%
Sub-Saharan Africa	21%
Turkey/Middle East/ Northern Africa	12%
China/Mongolia	12%
Afghanistan/Iran	11%
Middle South America/Philippines	8%
Surinam	6%
Reason to come to The Netherlands	
Political reasons	57%
Economic reasons	14%
Personal reasons	29%
Employment status	
Unemployed	78%
Full-time or part-time job	22%
Literacy	
Difficulties reading and writing	19%
Mean duration of residence in The Netherlands	5. 55 (3. 18 SD)
Mean duration of residence without documents	2. 86 (2. 86 SD)

[a] One illegal woman did not know her age.

Table 2: Characteristics of pregnancies of 27 illegal women[a]

First antenatal visit	
First trimester	15 (55%)
Second trimester	4 (15%)
Last trimester	3 (11%)
No antenatal visits	5 (19%)
Deliveries	n= 18[b]
Place of birth	
Hospital	10(56%)
At home	6 (33%)
Outside The Netherlands	2 (11%)
Preterm delivery	2 (11%)
Caesarean section	2 (11%)
Low birth weight< 2500 gr	2 (11%)

[a]If women had multiple pregnancies during illegal residence, the first pregnancy is included in the table.

[b] 9 women were still pregnant during the interview.

Obstacles in accessing care

Five women never attended an antenatal clinic, and three women started antenatal visits in the third trimester of their pregnancies. For five women, this was caused mainly by a lack of information; they were not informed about their rights on pregnancy care or were not familiar with the Dutch health care system.

> *"Only after I got in contact with the voluntary support organization, I realized that I was entitled to pregnancy care."*

One participant seemed uninformed or misunderstood the information:

> *"My lawyer told me that I have to wait till the 37th week of my pregnancy before I can get pregnancy care."*

For two women, fear for deportation was the main reason for not receiving antenatal services. One of the women sought prenatal care in her seventh month of her pregnancy at a hospital in Rotterdam, where they sent her away:

"They told me that I could not give birth in the hospital. They told me I should go back to Morocco. I was afraid. My neighbour drove me to Spain since we were informed that obstetric help was provided to illegal immigrants in that country."

In one woman, extreme difficulties with living circumstances prohibited her to seek prenatal help.

"I was so busy to survive, to find food, and shelter. I simply did not think of antenatal checks at all."

Some women that attended antenatal facilities more regularly experienced difficulties as well. One woman told us that her Dutch partner had to contact several practices before she could receive prenatal care.

Women who did receive prenatal care only reported problems related to bills; eight women reported such problems. In most cases, these were bills from midwives. Three women, or their partners, paid for the costs of the delivery themselves. One woman planned to go back to her country of origin to deliver because she was afraid she could not pay for the delivery. Two women were confronted with bills of several thousand Euros from secondary care institutions. One woman who underwent a cerclage in the second trimester of her pregnancy because of an incompetent cervix reported:

"They sent me a bill of 4000 Euro. I have no money, but I am afraid they will refuse further help if I do not pay."

Family planning and abortion

Eighteen per cent of the 77 women (14), 18-44 years of age, underwent an abortion while illegal in The Netherlands (Table 3). Five women (6.49%) had an abortion for less than 1 year ago. We calculated an abortion rate in our study population of 64.9 per 1000 women during the year before the interview.

Lack of money and lack of proper information were mentioned as the most frequent reasons for not using contraception or for undergoing an abortion.

Table 3: Self-reported contraception use and abortion in women 18-44 yrs of age

	N=77
No use of contraception	48[a] (62%)
Unmet need for contraception	14(29%)
Use of contraception	27(35%)
Oral contraception	11 (41%)
IUD	8 (29%)
Condom	5 (19%)
Sterilization	2 (7%)
Depo-Provera	1 (4%)
Ever had health education about contraception	38[b] (52%)
In The Netherlands	21(55%)
In home country	14(37%)
From family/friends	3(8%)
Abortion in history	23 (37%)
Abortion while illegal	14(18%)
Abortion < 1 year ago	5[c] (7%)

a=5 missing

b=2 missing

c= abortion rate per 1000 women (18-44 yrs) 64.9

"I would like to use an IUD, but I do not have enough money."

"I am afraid that I will become infertile through contraception."

Because of fear for high pregnancy care costs, two women reported that they decided to choose for an abortion. They were not informed about the possibilities to get pregnancy care for illegal women.

Further fear for deportation was reported.

"I bought an IUD, but I am afraid to go to the hospital to get in inserted."

"I was afraid to be arrested. Therefore, I had an abortion performed using the name and insurance papers of my documented sister."

Finally, women reported that they were not in control themselves.

"I am not allowed to use contraceptives by my husband."

Three persons reported that they were forced to have an abortion, one by her Dutch partner and two by a voluntary support organization.

"I wanted a baby, but the support organization forced me three times to go for abortions because it was too expensive and complicated to get a baby."

Preventive screening

Only 15% of the women in our study reported that they ever had a Pap smear in their life (Table 4). Several women (*n=7*) spontaneously mentioned that they were concerned about the possibility of having STDs or cervical cancer. They all wanted a gynaecologic examination, but did not succeed in obtaining an examination.

Gynaecologic problems

Gynaecologic problems were very common. Seventy percent of all women had one or more gynaecologic or sexual problems, as follows: lower abdominal pain, 42%; vaginal discharge/itching, 29%; urinary incontinence, 29% and menstruation problems, 20%.

Sexual health and violence

Twenty- eight per cent of the women reported that they experienced sexual violence and 45% reported that they experienced physical violence in the past. This percentage was significantly higher if the women were not accompanied by somebody during the interview (sexual violence, 38% and physical violence, 56%) (Table 5). Although we did not specifically ask about domestic or intimate partner violence, 15%, 10%, and 5% spontaneously reported domestic violence, intimate partner violence, and violence by other family members.

Five women reported that they had worked in prostitution. Additionally, several women mentioned that they knew illegal friends or family members who were forced to work as prostitutes.

"My friends told me that they prostitute themselves to earn money. I pray to God that this will never happen to me."

Table 4: Preventive screening in total population (*n*=100)

Test	*n*=100
PAP smear done in the past	15 (15%)
Indication for routine screening(30-64 yrs)	n=52
Pap smear done in the past	14(32%)
No PAP smear in the past	36(69%)
Patient is unsure	2 (4%)
Hepatitis B screening	
Yes	34 (34%)
No	33 (33%)
Patient is unsure	33 (33%)
HIV screening[1]	
Yes	27 (28%)
No	48 (46%)
Patient is unsure	27 (28%)
STD screening[2]	
Yes	19 (25%)
No	36 (47%)
Patient is unsure	22 (29%)

1: 5 missing

2 : 21 missing; no sexual contact or did not understand question

Fourteen per cent reported having sexual problems; 9% suffered from dyspareunia, 4% expressed loss of libido, 1% suffered from vaginismus, Seventy one per cent of these women had a history of sexual violence Three per

cent spontaneously mentioned that they underwent female genital mutilation before immigration to The Netherlands.

Table 5: Self-reported sexual and physical violence in total population (N=100)

	Alone during interview (*n*=50)	Accompanied (*n*=50)
Experienced sexual violence	19(38%)	9(18%)(p=0.026)
Experienced physical violence	28(56%)	17(34%)(p=0.027)

DISCUSSION

The reproductive health status of illegal female immigrants in The Netherlands is worrisome. Our results show a lack of or delayed prenatal care, low use of contraception, high abortion rates, low rates of Pap smears and STD screening and untreated sexual and gynaecologic problems. Illegal female immigrants are not able to exercise control over their own reproductive and sexual health for the following reasons: lack of information about reproductive health services and contraception; problems with financing of services; sexual and physical violence; and fear of deportation. Access to health facilities for illegal immigrants is problematic in many countries[6,15-19]; therefore, it is reasonable to expect that the reproductive health status of illegal female immigrants is a problem in these countries.

The Population Action (2007) stated that The Netherlands is one of the safest countries for women's sexual and reproductive health.[20] Yet, there is a rising trend of STDs and abortions among immigrants and the risk of severe acute maternal morbidity and maternal death is increased among immigrants.[21,24;23]

For illegal women, the need for improvement of and access to sexual and reproductive health services is evident. Among our study population, the abortion rate (64.9/1000 women) was much higher than the average abortion rate in The Netherlands (8.6/1000 women) and among asylum seekers with legal

status (14.4/ 1000 women).[25] The abortion rate is also higher than the recent worldwide estimate (29/1000).[26] Furthermore, we found high rates of delayed prenatal care. Inadequate use of antenatal care is also described for legal ethnic minority groups in The Netherlands by Choté et al.,[27] but our results were even worse, also compared to earlier studies among illegal immigrants;[5,9,11] The sample of pregnant women in this study was too small to associate the clinical significance of these findings with the outcome of the pregnancies and maternal morbidity. However, in other studies, poor access to prenatal care was related to a higher risk of pre-eclampsia[28], labour complications,[9] foetal distress,[9] and maternal deaths.[29]

Preventive screening rates for STDs and Pap smears were very low. Several studies have shown that among poor and immigrant women, the prevalence of cervical cancer is higher than the general population.[30-34] Therefore, illegal women should be considered to be at increased risk for cervical cancer. Yet, in our study population, only 27% of the illegal female immigrants reported having had a Pap smear at least once in their lives, whereas the 5-year coverage rates of cervical cancer screening in The Netherlands are 77%.[35]

This study was conducted between 2006 and 2008. In January 2009, the policy and financial coverage for costs of medical treatment for illegal immigrants changed. Since then, reimbursement of secondary care is also possible; although restricted to designated institutions, reimbursement for primary care costs is now possible for 80% of the costs. Costs for pregnancy care remained fully covered, and treatment for pregnancy-related problems is under conditions also possible in nondesignated hospitals. We believe that access to health care for pregnant women did not substantially change since January 2009, because regular pregnancy care was already covered. Access to secondary pregnancy care in hospitals after referral by a midwife or GP probably improved somewhat, because the thresholds diminished. In contrast, many hospitals that provided

pregnancy care to illegal women in the past will refer women to designated hospitals now that may be located far away from their residences.

There were some limitations in our study design and data collection. This was an exploratory study. It involved only 100 women purposively-recruited patients. Therefore, conclusions should be considered cautiously.

For the qualitative data, a participatory approach in this group is preferred. The interviews ideally should have been conducted in the women's own language by somebody from her own culture. Unfortunately, because of the diversity in origin, this approach was not feasible. Additionally, in the pilot study, telephonic interpreters were a hindrance in the interview. However, in some cases, we were confronted with communication problems. Some women turned down official interpreters for security reasons and preferred translation by family members. This made in-depth interviews more difficult. Furthermore, we decided not to audiotape the interviews in order not to lose the trust of the participants who are usually very concerned about their security. For the same reason, we allowed the women to be accompanied during the interview. Unfortunately, this certainly influenced the outcomes of the study. Because the women were asked to discuss some very sensitive topics (sexual health and violence), they were probably reluctant to discuss these things in the presence of males.

Very few studies were conducted that involved undocumented immigrants themselves. This is the first study that also included undocumented women that had not been able to make contact with health care professionals or support organizations. Therefore, we believe the results contain important information. Although this study was unique in our search for 'invisible' women, we were not always successful in that. Finding illegal sex workers, illegal labour migrants, and illegal family members of legal migrants proved very time-consuming and difficult. Therefore, there is a group of illegal women who still remained invisible' and of whom we have very little information. Unfortunately,

we have reasons to believe that their reproductive health status is even more vulnerable.

General practitioners, midwives, and other health care workers should be aware that undocumented women are at increased risk for HIV and other STDs. Most undocumented immigrants are not or not completely screened for these diseases, including HIV and cervical carcinoma. This requires an active role. If GPs do screen the illegal female immigrants, the percentages of positive tests are strikingly high.[36] Further, sexual and physical violence are common. Because of the important health consequences, routine screening for exposure to violence in illegal women is advisable, especially in women with sexual problems. For physicians, it is important to realize that often a woman will not disclose violence if she is accompanied by another person.[37]

According to article 12 of the United Nations International Bill of Rights for Women[2] and the definition of health by the WHO, women should have the freedom to decide if, when and how often to become pregnant;[38] illegal women do not have that freedom. Policymakers should be aware of that. These women should be empowered to gather that freedom through education. Further strengthening of personal skills to control and improve their lives could reduce their vulnerability. Further research is recommended to explore how empowerment can be achieved effectively in this specific group. Lastly, obstacles in accessing reproductive health care need to be removed as well.

Current knowledge on the subject

Little is known about the reproductive health status of illegal women and if they are able to exercise control over their sexual and reproductive life. Access to reproductive health facilities is problematic for illegal immigrants in many countries. Earlier studies showed delayed pregnancy care, a higher risk of pre-ecclampsia, labour complications, foetal distress, and maternal deaths. These

studies took place in health care facilities. No information is obtained from "invisible"; illegal women, the group that is too afraid to come to a doctor.

What this study adds

In this study, illegal women were interviewed. "Invisible" women were actively sought. The study provides information about the specific problems illegal women encounter in the control over their sexual and reproductive lives. The results show that the reproductive health status of illegal women is worrisome. Illegal immigrant women are not able to exercise control over their own reproductive and sexual health. There is an urgent need to empower illegal women by informing and educating them.

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Chapter 5

Undocumented female immigrants in the Netherlands have difficulties accessing TB health care

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Letter Submitted

To the Editors:

Immigrants in countries with a low-incidence of tuberculosis (TB) have a substantially higher risk of TB than nationals.[1] It is likely that the risk is even higher among undocumented immigrants because their living and migration conditions are often worse.[2] It is estimated that 112,000-165,000 undocumented immigrants live in the Netherlands.[3] Many undocumented immigrants originate from countries with a high prevalence of multi-drug resistant (MDR) or extensive drug-resistant (XDR) TB. The exact incidence of TB among undocumented immigrants is unknown in the Netherlands. In 2002 and 2003, 7% of the registered TB patients were undocumented immigrants.[4] TB control for undocumented immigrants is important, especially in view of the emerging problem of MDR TB and XDR TB.[5]

For asylum-seekers and regular immigrants from countries with a high incidence of TB, a routine entry screening for TB with chest radiographs is in place in the Netherlands and the yield is high.[6] However, there is no procedure for undocumented immigrants. Clearly, systematic screening in this group is very difficult. Most undocumented immigrants hide within the society because of a permanent fear of being arrested by the police. The undocumented immigrants are essentially invisible to health care organisations. Yet, undocumented immigrants are fully entitled to free TB care in the Netherlands.

We determined the TB screening rates and obstacles in accessing TB control facilities reported by undocumented women living in different cities in the Netherlands who were involved in our study on health status and access to health care in the Netherlands.[7;8] One hundred undocumented women $\geq$ 18 years of age originating from 32 different countries and living in various parts of the country participated in the project. The interviews were conducted between 2006 and 2008. Participants were recruited through a number of different (voluntary) support organizations and health professionals. We made an intense

effort in this study to find "invisible women" (women who were not in contact with health facilities or support organisations). We found these women through shelter homes, religious centres, a domestic workers organization, recruiting posters, advertisements in local newspapers, and snowball sampling. Diversity was sought according to age, country of origin, and reason for being undocumented. Participants in this project, with the exception of rejected asylum seekers who were all screened on entry, were interviewed for TB screening, TB-related health problems, and problems experienced when seeking help for possible TB-related health problems. Women with TB-related problems were referred to appropriate health care institutions. Data analysis was performed on SPSS for Windows (version 16.0; SPSS, Inc., Chicago, IL, USA). A Pearson chi-square test was used to compare the screened and non-screened groups. Informed consent was obtained from all respondents and the study protocol was approved by the Radboud University Nijmegen Medical Centre Ethical Committee (CMO).

Of undocumented women that reside in the Netherlands for economic or personal reasons (marriage or family reunion), 33% were screened at least once for TB (Table 1). This group constitutes approximately two-thirds of the total group of undocumented immigrants.[3] Unscreened women were less frequently in contact with a voluntary support organisation or registered with a general practitioner (GP). Twenty-two of 29 unscreened women came from countries with a high-burden of TB, 12 of which were from high-burden countries for MDR or XDR TB as follows: China, n=4; Philippines, n=3; Nigeria, n=2; Russia, n=2; and Georgia, n=1.[9]

Three of 43 women reported severe TB-related symptoms, such as coughing haemorrhagic sputum, night sweats, and weight loss. All of the 43 women refrained from accessing TB control facilities because of a fear of bills fear of deportation, or lack of information about the Dutch health care system. The 43 women were referred to us by a GP or TB screening facility. We have no

information if TB was indeed detected because we lost contact with all of these women.

The Working Group on Transborder Migration and TB of the International Union Against Tuberculosis and Lung disease recommends that health authorities should ensure easy access to facilities where undocumented TB suspects can be diagnosed and treated without fear of being reported to the police.[10] Currently, our study indicates that this is not guaranteed in practice in the Netherlands. In particular, women who are "invisible" for health care and support organisations are seldom screened for TB and refrain from accessing TB control facilities. This was a small exploratory study. Conclusions on numbers should be taken cautiously. Nevertheless, we believe that access to TB control facilities for the many thousands of "invisible" women in society is comparable to our study population or even worse. We observed that finding illegal sex workers, undocumented labour immigrants, and undocumented family members of legal immigrants was extremely difficult. Some women proved too afraid to participate in our study or did not show up. These women avoid all contacts with the Dutch society and are even more reserved with strangers than other undocumented women. We have reasons to believe that their access to TB control facilities for health care is even more problematic.

To diminish future problems with drug-resistant TB in society and related health hazards for undocumented immigrants, we believe undocumented immigrants need to be found, supported, and informed. Voluntary support organizations could play an important role in this. The recruiting system that we used in our project could be used to find these women. Further, we recommend to offer TB screening to undocumented immigrants who actually visit regular health care facilities. Awareness of the risk of TB needs to be increased among undocumented immigrants, emphasising that screening and treatment are free of charge for undocumented immigrants in the Netherlands and that health staff

have an obligation of confidentiality. Further, it is necessary to look carefully to institutional obstacles, e.g. asking for identification.

Table 1: TB Screening percentages of undocumented women residing in the Netherlands for non-political reasons related to different patient characteristics. N=43

	Screening TB	p value
General study population	33%(14)	
Contact with voluntary support organisation		
Yes (n=13)	77%(10)	p<0.001*
No (n=30)	13%(4)	
Registered with a GP		
Yes (n=16)	50%(8)	p=0.06
No (n=27)	22%(6)	
Language proficiency in Dutch		
Good (n=13)	*38%(5)*	p=0.587
Poor(n=30)	*30%*(9)	
Employment status		
Full time or part-time job (n=14)	36%(5)	p=0.290
Unemployed (n=32)	19%(6)	

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Chapter 6

Health care utilization and problems in accessing health care of female undocumented immigrants in the Netherlands

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ABSTRACT

Objective To obtain information about the actual use of health care facilities by undocumented women and to identify obstacles they experience in accessing health care facilities.

Methods A mixed methods study, with structured questionnaires and semi-structured interviews, was chosen to obtain a complete understanding. One-hundred undocumented women were recruited. Diversity was sought according to age, origin and reason for being undocumented.

Results Undocumented female immigrants have unmet health care needs (56%) and low health care utilisation. Sixty-nine per cent of the women reported obstacles in accessing health care facilities. These included many personal obstacles such as shame, fear and/or lack of information. Poor language proficiency (OR 0.28; CI 0.09–0.90) reduces utilisation of primary health care services.

Conclusion Health care utilisation of undocumented women is low. Undocumented women refrain from seeking health care because of personal obstacles. These women need to be identified and informed about their rights, the health care system and the duty of professional confidentiality of doctors. Finally, institutional obstacles to access care should be removed since they strengthen reluctance to seek help.

INTRODUCTION

An estimated number of 1.9–3.8 million undocumented immigrants live in Europe.[1] In the Netherlands, estimations range between 75.000 and 185.000 undocumented immigrants.[2] Undocumented immigrants are people without any residence permit authorising them to stay in the country of their temporary residence. These people experience health problems related to their origin and present situation.[3-7] The right to health care is a human right recognised by the UN international covenant on Economic, Social and Cultural rights.[8] States are under the obligation to provide equal access to preventive, curative and palliative health services for all persons, including undocumented.[9] Despite this, specific legislations, regulations and laws make access to health facilities for undocumented immigrants problematic in many countries.[7,10-20]

In the Netherlands, undocumented immigrants have no right to obtain health insurance but are entitled to receive ''medically necessary care'' that is defined as responsible and appropriate medical care as indicated by the treating doctor.[21] At the time of this study, between 2006 and 2008, GPs, midwives and pharmacists could get full reimbursement for unmet costs from a special fund if the undocumented immigrant was insolvent; hospitals could receive reimbursement by means of so-called 'dubious debtors' provisions. Hospitals had to negotiate with health insurance companies about compensation for unpaid bills of insolvent patients. Otherwise, no fund covered ambulant mental care, dental care and residential nursing care. TNO health concluded in 2001, based on interviews with health care professionals, that these financial arrangements in general raise no obstacles accessing health care.[22] Nevertheless, serious doubts about the accessibility of health care for undocumented immigrants remain. Health care seeking behaviour and access to health care are influenced by many factors other than legal and financial.[23-25] Most information about access to health care in undocumented immigrants in earlier studies was obtained from health care institutions and health care professionals.[7,14,17,19,20,26,27] In order to

understand the problems in accessing health care and influencing factors, research among the population of undocumented immigrants themselves is necessary. Unfortunately, these data are scarce[10,11,15] as the World Medical Organisation (WMA) recently concluded.[28] Therefore we decided to study this gap in the knowledge. We focussed on undocumented women since in comparison with male persons their vulnerability is even greater and data about access to health care are even scarcer. Undocumented women have many different health problems and rate their health as very poor.[29] Especially, gynaecological and psychosocial problems are prevalent. Therefore, adequate access to health care facilities is important for females. We were particularly interested in the experiences of women who were not in contact with health care professionals. Therefore, we decided to recruit and interview different undocumented women from different backgrounds. Our aim was to obtain information about the obstacles faced by undocumented women in accessing health care facilities and about the extent of the problem: the actual use of health care facilities by this group.

METHODS

Study design

We opted for a mixed method study, with a structured questionnaire about the use of health care services and a semi-structured interview about obstacles experienced in accessing health care. Tracing undocumented immigrants and conducting research in this group is time-consuming and very difficult. Participants' trust should be gained and their safety should be guaranteed. Obtaining quantitative data about the use of health care facilities and qualitative data about obstacles in accessing health care facilities at the same time was efficient and implicated minimum inconvenience for the participants. But more important, this method provides a better understanding of the problem.

We used a triangulation design model, with equal priority for qualitative and quantitative data.[30] Participants were purposively recruited.
This study was part of a larger project that evaluated the feasibility of introducing patient-held records for undocumented immigrants.

Study population

Undocumented women aged ≥ 18 years, living in different parts in the Netherlands, were purposively recruited through voluntary support organisations, general practitioners (GPs), a domestic workers organisation, shelter homes, churches and midwives. To find women not yet identified by health professionals or an organisation, advertisements were placed in local newspapers and recruiting posters were placed in locations frequented by immigrants. Further, we made use of snowball sampling: we asked participants with whom contact had been established to refer to us other females who could potentially participate. After successfully enrolling 80 women this way, we stopped the recruitment and we evaluated the composition of the study population. Variation in age, country of origin and reason for being undocumented was judged. After that we exclusively looked for undocumented women that were underrepresented in the study population according to the estimates of different groups of undocumented women in the Netherlands: undocumented labour migrants and victims of human trafficking.[2] Undocumented women that contacted us and showed interest to participate in our study received an explanatory letter in their own language. The research assistant contacted all women by telephone to clarify the purpose of the study more in detail. If the women agreed to participate an appointment for an interview was made. We provided all participants with free medical advice and assisted in finding a GP.

Data collection

Interviews were conducted in primary health care facilities or in the person's temporary shelter. The interviewer was a skilled research assistant. To women that were unable to communicate in English or Dutch sufficient interpretation was offered. The participants were informed that their answers would be processed anonymously. Given the fact that it was very difficult to gain the trust of the women as many of them were afraid of being arrested by the police, we decided not to audiotape the interviews. Socio-demographic information was obtained at the start of the interview and included data about country of birth, marital status, children, housing conditions, occupation, education, duration of residence in the Netherlands and reason for staying in the Netherlands. Data about use of health care services were obtained through a structured questionnaire. In order to explore obstacles experienced in accessing health care, a semi-structured interview was held. The interviewer followed an interview guide composed by an expert panel. The interview guide contained the following themes: reasons for not-using health care facilities and obstacles encountered in accessing facilities. Field notes were made and member checking took place after the interview.

Data analysis

Data analysis was performed after all data (i.e., both qualitative and quantitative data) had been collected: parallel/ simultaneous design. The quantitative data were analysed using SPSS for windows (version 16.0, Spss Inc, USA).

Two-tailed Pearson Chi-square tests were used to examine the relations between use of different health services and the following variables: age, marital status, having children or not, country of origin, employment status, capability of speaking Dutch, duration of undocumented stay in the Netherlands, reason for staying in the Netherlands and self-rated health. Multivariate logistic regression

analyses were performed by entering all variables that reached p values <0.20 in univariate analysis, to identify the factors that were independently associated with the use of health services.

Two authors (MS and ML) independently analysed the data of the semi-structured interviews. After familiarization with the data, the researchers carried out thematic analyses to identify and categorise major themes and subthemes.

The notes, field notes and transcripts were independently coded and subsequently the researchers defined the most important themes together. In case of disagreement both researchers tried to reach consensus by discussion. In case of a remaining dispute a third researcher (MvdM) was consulted.

Approval from the study was obtained from the Radboud University Nijmegen Medical Centre Ethical Committee (nr: CMO 2005/204).

RESULTS

Of the 100 women participating in the study, 47 lived in a semi-rural area in the south east of the Netherlands (Nijmegen, Den Bosch) and 53 in a large city (Amsterdam, Rotterdam, The Hague) (Table 1).

For 13 women we used a qualified interpreter and for 24 women a relative was interpreting. Though we preferred to interview the women alone, 50 women came, for practical or security reasons, to the interview accompanied by one or more children (9), their partner (12), a volunteer (5), a female family member or friend (20) or a male family member or friend (4). In order not to lose the trust of the women we allowed these companions to attend the interview.

Use of health care facilities

Eighty percent of the women mentioned to have experienced health problems during their stay as undocumented immigrant. 39% (31) of these women received medical care for these problems, 56% (45) said they received no care

for these problems, and 5% (4) reported that they received care for some problems but not for all.

Table 1 Characteristics of study population %/mean (SD) (*n* = 100)

Age (years)[a]	36.4 (14.7)
Children	73
Partner	
Yes	53
Religion	
Christian	62
Muslim	23
Hindu	3
Buddhist	2
No religion	10
Country of origin	
Europe	37
Asia	29
Africa	25
America	9
Reason to come to Netherlands	
Political reasons	57
Non-political reasons	43
Employment status	
Unemployed	80
Full time or par time job	20
Literacy	
Difficulties reading and writing	19
Mean duration of residence in Netherlands in years	5.55 (3.2)
Mean duration of residence without documents in years	2.86 (3.0)

[a]One missing, did not know age

Registration with a GP

56% (56) of the women were registered with a GP. Women that were supported by (voluntary) support organizations were registered with a GP in 81% (46) of

the cases, and women not supported by (voluntary) support organizations in 23% (10) (p = 0.000). Almost all women that were registered (40) found their GP with help of a voluntary support organisation; eight women found a GP through family members or friends, the others through churches, employers, other doctors and public health institutions.

Use of health care

Undocumented women that came to the Netherlands for political reasons (rejected asylum seekers) reported higher health care utilisation than women that came to the Netherlands for personal or economic reasons (Table 2).

Table 2 Differences in the use of health care services between undocumented immigrants for political and non-political reasons % (*n*)

	Total studied (*n* = 100)	Undocumented for political reasons (*n* = 57)	Undocumented for non-political reasons (*n* = 43)	*p* value
No use of professional health care services <1 year	13 (13)	7 (4)	21 (9)	0.041
Contact general practitioner <2 months	49 (49)	63 (36)	30 (13)	0.001
Contact outpatient specialist ever while undocumented	33 (33)	35 (20)	30 (13)	0.609
Contact with ambulatory mental health care <1 year	19 (19)	32 (18)	2 (1)	0.001
Contact dentist <1 year	33 (33)	42 (24)	21 (9)	0.026

Table 3 shows adjusted ORs for the associations between characteristics of the study population with p<0.2 in univariate analysis and contact with a GP <2 months. Women that did not speak the Dutch language reported fewer contacts with a GP (OR 0.28; CI 0.09–0.90). Women that rated their health as ''poor'' (moderate or bad) reported significantly more contacts with GPs in comparison

with women that rated their health as ''good'' (good, very good or excellent) (OR 4.89; CI 1.56–15.30). On the contrary, women that rated their health as ''poor'' reported fewer consultations with medical specialists in comparison with women that rated their health as good (OR 0.26; CI 0.08–0.77) (Table 4).

Table 3 Self-reported contact with GP in the last 2 months: logistic regression

Characteristic	Unadjusted OR (95% CI)	Adjusted OR (95% CI)
Age	1.03 (1.00–1.06)	1.02 (0.99–1.06)
Country of origin in		
Asia	0.29 (0.10–0.81)*	0.42 (0.12–1.42)
Africa	0.96 (0.34–2.71)	1.65 (0.44–6.11)
America	0.32 (0.07–1.48)	0.37 (0.04–3.09)
Europe	Ref	Ref
Language proficiency in Dutch		
Poor	0.36 (0.16–0.80)*	0.28 (0.09–0.90)*
Good	Ref	Ref
Self-rated health		
Moderate/poor	4.44 (1.78–11.05)*	4.89 (1.56–15.30)*
Good/very good/excellent	Ref	Ref
Reason for stay in the Netherlands		
Political reasons	4.15 (1.77–9.77)*	2.12 (0.65–6.91)
Non-political reasons	Ref	Ref

Each variable had been adjusted for all other variables in the table
OR odds ratio, *CI* confidence interval
* $p < 0.05$

Obstacles in accessing health care facilities

Sixty-nine women (69%) reported problems in accessing health care facilities. We identified two different categories of problems: (1) Institutional obstacles: obstacles put in place by health care facilities or aid organisations and (2) personal obstacles in accessing care; these are hindrances as felt by the person herself. Forty-seven women (47%) reported institutional obstacles and 40 women (40%) reported personal obstacles. Eighteen women reported problems from both categories. Institutional obstacles included:

Financial barriers

Invoices (up to 7,000 euro) were received from hospitals. Some women were confronted with a debt collection agency. These occurrences had a negative influence on their future health-seeking behaviour:

''I do not have enough money to go back to the hospital.''

Forced cash payment was experienced in primary care and at the pharmacy:

''I had to pay 75 euro before they even wanted to look at my sick child''

''I was forced to pay the doctor, after that I never went back''.

Women reported that operations, maternity care, examinations and nursing aid were cancelled since they were not insured and it was considered to be too costly.

Table 4 Self-reported contact with specialist while undocumented: logistic regression

Characteristic	Unadjusted OR (95% CI)	Adjusted OR (95% CI)
Age	1.03 (1.00–1.06)	1.05 (1.02–1.09)*
Country of origin in		
Asia	0.90 (0.31–2.64)	1.62 (0.47–5.54)
Africa	1.33 (0.45–3.91)	2.50 (0.68–9.16)
America	2.96 (0.67–13.13)	6.50 (0.87–48.58)
Europe	Ref	Ref
Language proficiency in Dutch		
Poor	0.41 (0.18–0.97)*	0.38 (0.13–1.14)
Good	Ref	Ref
Self-rated health		
Moderate/poor	0.51 (0.22–1.21)	0.26 (0.08–0.77)*
Good/very good/excellent	Ref	Ref
Reason for stay in the Netherlands		
Political reasons	0.80 (0.34–1.87)	1.87 (0.54–6.50)
Non-political reasons	Ref	Ref

Each variable had been adjusted for all other variables in the table
OR odds ratio, *CI* confidence interval
* $p < 0.05$

Refusal of services

In primary care women were refused admission as a patient, by the receptionist or by the GP in person, since they were unable to show identification papers:

''You are no longer insured, so you won't get an appointment'' (GP to a patient who lost her temporary residence permit).

Further, numerous women were refused help in an institution of secondary care:

''I had a surgery appointment for cervix carcinoma. But when I arrived at the hospital on the scheduled day I was sent away by the receptionist. I felt deeply humiliated.''

The mediation by volunteers was reported as an obstacle as well, in particular the need for authorization by the support organisation to go to the doctor:

''Appointments with the GP are made by the volunteer. This is unpleasant, because I need to tell her what my problem is... ''

Personal obstacles in accessing care included the following:

Lack of information

Women were not informed about their entitlements:

''I was not aware that it was possible for me to go to a doctor''

Furthermore, women experienced problems finding their way around in the Dutch health system:

''I did not know where to go, we did not know how things were organised, absolutely nothing and it was so difficult... ''

Fear for bills

This was an important obstacle in accessing health care. Many never visited a doctor for this reason.

''I never consult a doctor, because I have no money."

Fear for being reported to the police.

''I was afraid that the doctor would contact the police''

''I was too afraid to go to a dentist. Finally when I could no longer bear the pain I pulled the tooth out myself.''

Women were not informed that a health care professional in the Netherlands has an obligation of professional confidentiality and will not contact the police authorities.

Sense of shame

''It feels bad if you have to ask for help without being able to pay for it''

Health care no priority

For other women searching for food and shelter took all their energy. A woman who delivered without one single ante natal check mentioned:

''There were so many problems, I struggled to survive, I didn't even realise I could go to a doctor.''

DISCUSSION

Health care utilisation of undocumented female immigrants in our study is low. The majority of the women report unmet health needs (56%) and obstacles in accessing health care (69%). These included many individual obstacles such as fear, shame or lack of information. There is evidence that health care utilisation by the undocumented women in our study is lower than that by legal migrant women and female asylum seekers/refugees in the Netherlands.[31,32] This applies particularly to women that came to the Netherlands for personal reasons such as marriage and reunion with family or for economic reasons. Fifty-six percent of legal immigrant women had contact with a GP in the past 2 months versus 49% of our total study population and 30% of undocumented women that came to the Netherlands for non- political reasons. Contacts with medical specialists were even less frequent: 58.5 versus 33 and 30%.[32] The higher use of health care facilities by women that came to the Netherlands for political reasons (rejected asylum-seekers) can be partly explained by a better understanding of the Dutch health care system; during their stay in the asylum seekers centres they were entitled to regular health care and received information about the Dutch health care system. Also their contacts with voluntary support

organisations may contribute to this difference; these organisations play an important role in assisting undocumented immigrants to access health care in the Netherlands.

Factors associated with use of health services are age, language problems and self-rated health. The association between older age and increased health utilisation was found in other studies as well.[32,33] Language problems also influenced the health-seeking behaviour[15,20,34] of Mexican immigrants and Canadian immigrants in the US. The association between poor self-rated health and health care utilisation, however, is contradictory. Poor self-rated health was associated with more consultations with a GP, but with fewer consultations with medical specialists. Associations between poor selfrated health and increased health care utilisation are known from other studies.[33,35-37] The association between poor self-rated health and lower secondary care utilisation is new and surprising. Some studies report lower use of secondary care facilities by immigrants[24,38] and others a higher use,[32,39] but no studies report lower use by patients with poor self-rated health. Further studies are recommended to explore this detail.

Lower health care utilisation can be a problem for accessibility or can reflect differences in need. Our study clearly shows that problematic access to health care facilities for undocumented women is the main reason for the lower use. In our study population only 39% of the women expressed that they received adequate medical care for the health problems they experienced during their undocumented stay. Sixty-nine percent of the women report problems in accessing health care facilities. These problems subscribe the obstacles mentioned in several reports: rejection by GPs and specialists, discrimination, neglect, cancellation of surgeries and invoices.[14,17,19] Our study emphasises, however, also the influence of other than institutional blockades. Many undocumented women will never seek help due to personal blockades like fear for bills and deportation, shame and language problems. An important common

cause of all the above-mentioned individual blockades is a lack of information. Women were found poorly informed about their rights and entitlements, the Dutch health care system and the possibility of reimbursement for the health care professionals. These findings are in conformity with a recently published thesis of Baghir-Zada who interviewed 25 undocumented women about health needs.[10] Bills presented to women by GPs, midwives and pharmacists indicate that health care workers are not adequately informed about existing legislation and/or reimbursement of costs either.

There are some limitations in our study design and data collection. For the quantitative data, the most important limitation of our study is that a representative sample of undocumented women is not feasible. Undocumented women in the Netherlands are nowhere registered, and only estimates about the size of different groups of undocumented women in the Netherlands exist. Therefore, conclusions should be drawn cautiously. Selection bias may have been introduced by the method used for recruiting the sample. For the qualitative data there were some limitations in the data collection. The interviews ideally should have been conducted in the women's own language by somebody of her own culture. Unfortunately, because of the diversity in origin this approach was not feasible. As a consequence we were confronted with several communication problems. Some women turned down official interpreters for security reasons and preferred translation by family members. This made in-depth interviews more difficult. It is likely that some experiences remained unmentioned. Furthermore, we decided not to audiotape the interviews in order not to lose the trust of the participants that are usually very concerned about their security.

The strength of this study is that female undocumented immigrants were personally interviewed about health care utilisation. This group is very difficult to recruit since they live in permanent threat of being arrested by the police and

therefore hide in secret locations. As a consequence, policymaking for this group is often done without collecting and considering the opinions of the undocumented immigrants themselves. Our study gives clear information about the use of health care facilities and obstacles in accessing health care facilities based on the experience of undocumented female immigrants themselves, even from the women that refrain from seeking help and therefore are not included in most studies we mentioned before. There are unmet health care needs among undocumented immigrants. This study shows that clearing institutional obstacles in accessing care alone is not enough to improve and guarantee the use of regular health care. Especially female labour migrants and women that came to the Netherlands for marriage and family reunion experience additional obstacles in accessing health care. These often 'invisible' groups, not known by any voluntary support organisation, need to be found, supported and informed about their rights, the health care system and the duty of professional confidentiality of doctors. Also health care providers need to be informed about existing legislation and explicitly instructed that they are obliged to provide care to these people.

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Chapter 7

Patient-held records for undocumented immigrants: a blind spot. A systematic review of patient-held records

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ABSTRACT

Objective. As a result of inadequate medical record information, the medical care for undocumented immigrants in general practice is time consuming and often unsatisfactory. The availability of medical record information might improve the medical care for undocumented immigrants. Therefore, we executed a systematic review of literature to investigate the potential benefits of a patient-held record (PHR) for undocumented immigrants.

Design. We searched MEDLINE, EMBASE, PSYCH info and the Cochrane database of systematic reviews. Search terms were: patient-held medical records, client-held medical records, PHRs, client-held records, home-based medical record, medical passport and/or illegal immigrants, and undocumented immigrants. Inclusion criteria were: information on patient and/or doctors compliance of PHRs OR information about views of patient and/or doctors on PHRs AND age over 18 years. Two independent reviewers assessed the methodological quality of the selected articles.

Results. No studies were found about undocumented immigrants and PHRs. Therefore, we decided to eliminate the search terms illegal immigrants, and undocumented immigrants, and perform a broader search about the use of PHRs in general. This search yielded 61 articles; 42 articles were excluded. Sixteen six quantitative studies and one qualitative study. In these studies the use and appreciation of PHRs by patients is satisfactory. The use and appreciation of the PHRs by physicians in the studies is lower than the use by patients. The most important obstacle for physicians is the time investment required.

Conclusion. A PHR for undocumented immigrants seems to be appropriate because in most cases there is no other record available. However, the uncertainty of our findings is considerable. Therefore, we recommend a pilot evaluation of the use of PHRs for undocumented immigrants. In addition, a qualitative approach might be useful to solicit the views of undocumented immigrants and health care workers.

INTRODUCTION

In the Netherlands, as in most wealthy areas of the world, illegal immigration is common. An estimated 112,000-163,000 undocumented immigrants live in the Netherlands.[1] New legislation in 1998 made it impossible for undocumented immigrants in the Netherlands to obtain the mandatory health insurance.[2] Therefore, their access to health facilities is probably limited. Unfortunately, little research has been done concerning undocumented immigrants and their health problems. Yet, we know that undocumented immigrants in many countries are often confronted with constraints to accessing health care,[3,4] while at the same time physicians experience great problems in providing standard care for this group.[5]

Complexity of problems, pitfalls in communication and extra workload are common hindrances. The care for undocumented immigrants in general practice is time consuming and often unsatisfactory, partly because of lack of adequate medical record information.

For vulnerable transient groups in our society like undocumented immigrants and the homeless, record keeping of sufficient quality is complicated. In these groups, access to health services is not available in a traditional manner. Patients often visit different physicians in different places. Therefore, it is difficult to obtain medical record information about patient history, test results, X-rays, and medication and management. The absence of this information is likely to influence the quality of care, because continuity of care contributes to a better quality of care. Accumulated general practitioners' (GP) knowledge about their patients is a substantial factor in saving time, referrals and reduction in the use of medication.[6]

Our hypothesis is that the availability of medical record information will improve the care for undocumented immigrants and will decrease medical costs.

Furthermore, it will save time and make the care for undocumented immigrants more satisfactory for professionals.

Since undocumented patients often move to other cities or seek help from different doctors, the medical record information should be available at any time in any place for all medical professionals. Therefore, during the time that a nationwide electronic medical record is not available, a computer-based record system, such as developed for the homeless, is not an appropriate solution for the undocumented immigrants because undocumented patients often move to other cities and doctors.[7,8] Furthermore, it is very important that medical and personal information are kept confidential for this particular group. It would be preferable for undocumented patients to keep their medical records in their own possession. The possession of a patient-held record (PHR) may decrease uncertainty in patients and may give them more command of their own health.

Studies among women holding their own maternal records found that these women were more likely to feel in control of their antenatal care.[9,10] PHRs improve communication and increase trust, both of which involve patient autonomy.[11] Providing undocumented immigrants with a medical record will probably enhance the continuity of care as well as the empowerment of patients. However, these positive results will only occur if the PHR is used correctly and if patients and doctors believe in the positive effects of the PHR. For that reason we are interested in the potential benefits of the use of a PHR.

With these aims we systematically reviewed the literature on two questions:

Do undocumented patients and their physicians keep and use a PHR?

What are the experiences of physicians and patients with a PHR?

METHODS

We searched MEDLINE (1986-April 2007), EMBASE (1986-April 2007), PSYCH info (1986-April 2007) and the Cochrane library with no language restriction. Search terms were chosen by an expert panel and included: personal medical record OR PHR OR client-held record OR home-based medical record OR medical passport AND illegal immigrants OR undocumented immigrants.

Because we did not find any publications about the use of PHRs in undocumented immigrants, we decided to eliminate the search terms 'illegal immigrants' and 'undocumented immigrants', and perform a broader search of the above mentioned databases and other sources about the use of PHRs in general. Search terms were: personal medical record, patient held record, client-held record, home-based medical record, and medical passport. We supplemented this search strategy by checking the reference lists of all retrieved articles for additional articles. To select studies for further assessment, the first author (M. Schoevers) reviewed the title and abstract of every record retrieved. Articles were selected if this information indicated that the study met our eligibility criteria. If there was doubt regarding the title and abstract information, the full article was retrieved for clarification. M. Schoevers and M. van den Muijsenbergh examined the remaining full text reports for eligibility criteria. Disagreements were handled by consensus. The following inclusion criteria were used: containing information on patient and/or doctors compliance of PHRs OR containing information about views of patient and/or doctors about PHRs AND age over 18 years. Because we aimed to gather information about both compliance and experiences and views of doctors and patients, we opted for liberal study design criteria. We included (cluster) randomized controlled trials as well as surveys, descriptive studies, pilots and qualitative studies.

Articles that focussed primarily on prevention and health promotion were excluded as well as articles that investigated medication cards or mini records. In addition, articles about nursing records were excluded, because we focussed

primarily on the medical record information of and for GPs and medical specialists. Quality assessment of the studies that met the eligibility criteria was done by the two reviewers (M. Schoevers and M. van den Muijsenbergh) independently. Possible disagreement was resolved by consensus or by a third reviewer in case of persisting disagreement (A. Lagro-Janssen). We assessed the following quality items:

1. Are the eligibility criteria of the study clearly specified? Is confounding minimised? (referring to selection bias).
2. Is the compliance rate unlikely to cause bias? (completeness of sample, follow up; referring to attrition bias).
3. Are the outcome measures unbiased and correct assessed? (referring to detection bias).

Each item was scored with two points if it was well described in the article and there was no evidence for bias, with one point if it was partly described or unclear and with zero points if it was not described or bias was likely to be present. Qualitative studies were evaluated by four criteria developed by Giacomini and Cook:[12]

1. Are participants relevant to the research question and was the selection well reasoned?
2. Are the data collection methods appropriate for the research objectives and setting?
3. Is the data collection comprehensive enough to support rich and robust description of the observed events?
4. Are the data appropriately analysed and the findings adequately corroborated?

Also here, each item was scored with two points if it was well described in the article, with one point if it was partly described or with zero points if it was not described. Two researchers (M. Schoevers and M. van den Muijsenbergh) scored the studies independently. The final score was made by consensus. Articles were only included if they had a score of at least half of the possible

points: three or more for quantitative studies and five or more for qualitative studies.

RESULTS

The computerised search yielded 104 publications, and an additional 14 articles were found by checking the reference list of all the retrieved articles. Figure 1 shows a study flow diagram. Forty-two articles were excluded because they did not meet the eligibility criteria. Many articles were found about medication cards or mini records (eight), parental-held records (six) and health promotion or prevention (eight). A review about patient-held records in cancer care focussed primarily on effectiveness and not on compliance.[13]

Sixteen articles were screened for methodological quality: 15 quantitative and one qualitative study.[14-29] Seven articles met the methodological quality criteria: six quantitative studies and one qualitative study.[18,22-26,28] These studies are shown in Table 1 and the excluded studies are shown in Table 2.

No studies were found regarding undocumented immigrants, our target population.

Figure 1 Study flow diagram

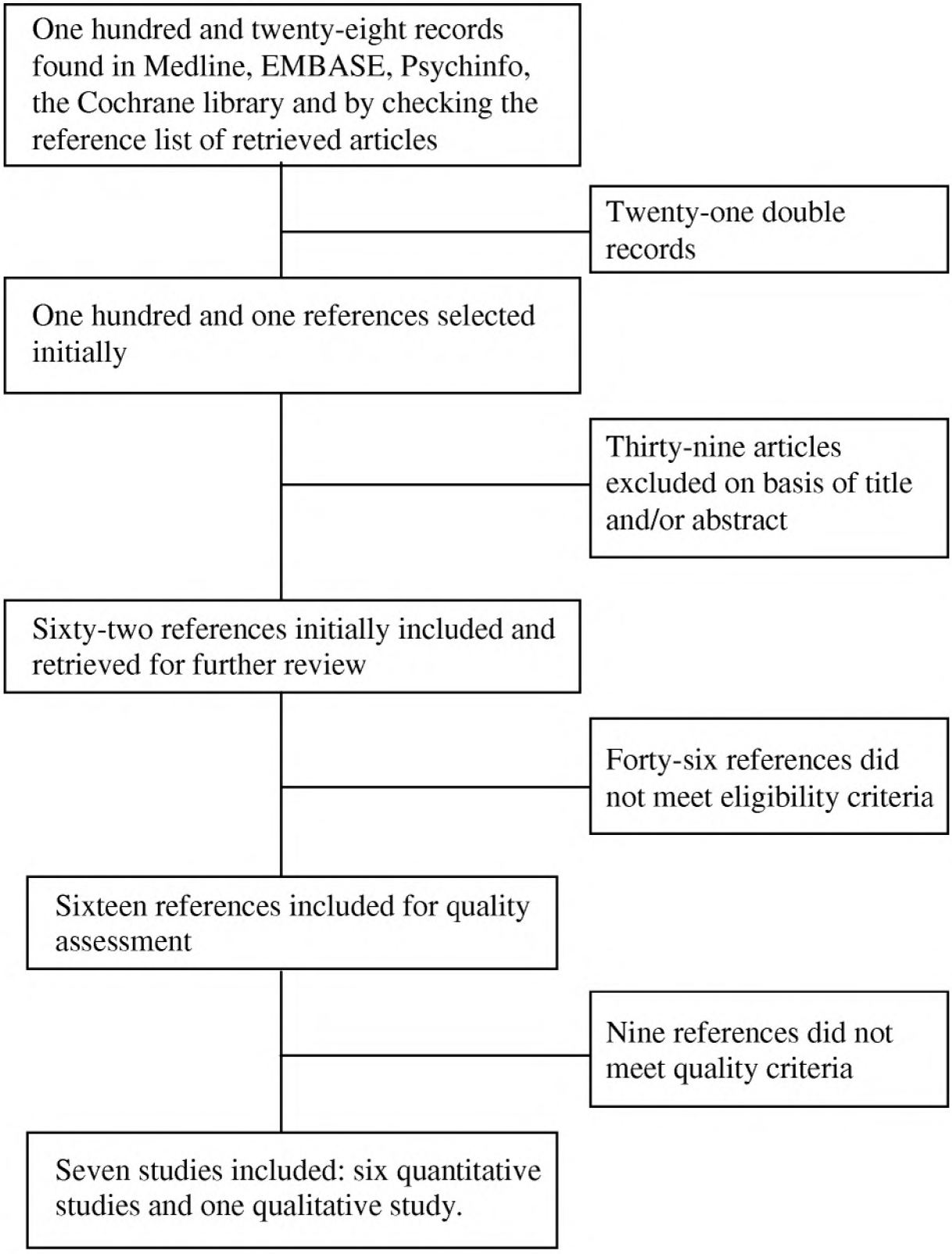

Table 1. Characteristics of the included studies.

First author (year)	Quality score	Type of study	Population	Information on patients' compliance	Information on doctors' compliance	Patients' view on PHRs	Doctors' view on PHRs
Lester (2003)	6	Cluster RCT	Patients with Schizophrenia (100)	Yes	Yes	Yes	No
Lecouturier (2002)	6	RCT	Patients with cancer (103)	Yes	Yes	Yes	Yes
Cornbleet (2002)	4	RCT	Patients with cancer (117)	Yes	No	Yes	Yes
Williams (2001)	5	RCT	Patients with cancer (251)	Yes	Yes	Yes	Yes
Warner (2000)	4	Cluster RCT	Patients with long-term mental illness (55)	Yes	Yes	No	No
Drury (1996)	4	Cohort study	Patients with cancer (43)	Yes	Yes	Yes	Yes
Dijkstra (2002)	6[a]	Qualitative study	Diabetes patients	No	No	Yes	Yes

[a]Qualitative study, scored by criteria of Giacomini and Cook (2000).

Table 2. The excluded studies and scores on the screening criteria.

First author (year)	Population	Minimisation of selection bias	Minimisation of detection bias	Minimisation of attrition bias	Final score
Dijkstra (2005)	Patients with diabetes	1	0	1	2
Stafford (2002)	Patients with long-term mental illness	0	1	2	3
Drury (2000)	Radiotherapy outpatients	1	1	1	3
Van Wersch (1997)	Patients with diabetes	1	1	1	3
Stafford (1997)	Patients with long-term mental illness	0	1	1	2
Van der Hoek (1994)	General population Zambia	1	1	0	2
Liaw (1993)	General population	1	0	1	2
Reuler (1991)	Homeless mentally ill	1	0	1	2
Giglio (1987)	General population	1	2	0	3

Do patients and their physicians keep and use a patient-held record (PHR)?

Patients

Table 3 shows the usage of PHRs by patients. Most studies reported the percentage of patients who were still in possession of their PHR after the follow-up period. This percentage differed from 61% after one year for long-term mentally ill patients[22] to 100% in cancer patients.[26] In some studies, patients were only asked whether they used the PHR or not; in other studies usage was specified in reading, writing in it or bringing it to appointments. Usage of the PHR in general varied from 44% in long-term mental illness patients[22] to 93% in advanced stage cancer patients.[21]

Table 3. Using of PHR by patients.

First author (year)	Population (*n*)	Follow-up	Percentage (%) still in possession of records	Percentage (%) using the records	Percentage (%) taking it to appointments
Lester (2003)	Patients with Schizophrenia (100)	One year/92	69	70	No data
Lecouturier (2002)	Patients with cancer (103)	3-6 months/68	100	87	66
Cornbleet (2002)	Patients with cancer (117)	4-6 months/80	No data	83	No data
Williams (2001)	Patients with cancer (251)	Six months/ 172	96	85	No data
Warner (2000)	Patients with long-term mental illness (55)	One year/46	61	44	No data
Drury (1996)	Patients with far advanced cancer (43)	Three months/30	100	93	80

Physicians

Table 4 shows the usage of PHRs by health professionals. Some studies recorded the use of the PHR by all professionals and others looked separately at GPs and medical specialists. The use of the PHR can be divided into use in

general and in a more specific use: reading or writing in the PHR. Looking into the PHR was most frequent (90%) among GPs of cancer patients[26] and lowest among professionals of patients with long-term mental illness (42%).[22] Writing in the PHR was again much higher among professionals of cancer patients (77%)[23] than among GPs of patients with long-term mental illness (27%).[22]

Table 4. Using of PHR by doctors.

First author (year)	Population	Type of doctor/setting	Percentage (%) using PHR in general	Percentage (%) reading in PHR	Percentage (%) writing in PHR
Lester (2003)	Patients with Schizophrenia	GP Specialist (Sp)	GP: 32.8% Sp: 31.3%	No data	No data
Lecouturier (2002)	Patients with cancer	Outpatient clinic (OPC)	No data	OPC: 78%	No data
		Hospital ward (HW)		HW: 48%	
		GP		GP: 90%	
Williams (2001)	Patients with cancer	Professionals (Prof)	No data	No data	Prof: 77%
Warner (2000)	Patients with long-term mental illness	Prof	No data	Prof: 42%	Prof: 27%
Drury (1996)	Patients with far advanced cancer	GP Sp	No data	GP: 60.0% Sp: 56.7%	GP: 33.3% Sp: 56.7%

What is the general opinion of patients and physicians on a patient-held record (PHR)?

Patients

In two studies, the general opinion of patients about the PHR was positive. Both studies related to patients with cancer. Drury found that the majority of patients with cancer thought that the record was helpful, 86% of all patients felt that the record was easy to use and no one thought it difficult to use.[18] In the study of Lecouturier, over half of all patients felt that the PHR had been helpful and of

some benefit to them, and 69% felt it would be useful in the future.[26] In three articles the general opinion about the PHR was neither clearly positive nor negative. More than half of the patients with cancer (53%) in the study of Williams preferred not to have a PHR.[23] In the study of Lester, more than half of the patients with schizophrenia (53%) expressed a desire to continue the usage of the PHR.[28] Diabetes patients varied considerably in their opinion towards the use of the diabetes passport.[25] Most patients seemed to welcome the idea of a PHR, but many had low expectations about initiating the project.

Physicians

The general opinion of the majority of health professionals of patients with cancer was that a PHR was useful. Drury found that 50% of the professional carers judged the PHR as very helpful and 29% as partly helpful.[18] In the studies of both Cornbleet and Lecouturier, the majority of the hospital staff (70 and 79%) thought that the PHR had been beneficial, but more to the patients than to themselves.[24,26] In comparison, most primary care staff viewed the PHR as of high and equal value to patients (83%), themselves (83%) and their work peers.[26]

Table 5 shows positive and negative views of both patients and physicians.

Positive views came mainly from patients with cancer. A few positive views came from diabetes patients and psychiatric patients as well. Positive views of physicians were only mentioned in one study,[23] and included that it facilitated communication.

Negative views and reasons for not using the PHR were fairly common. Many patients did not want to burden staff with the PHR. Lack of time and increase of paperwork was also reported by physicians. Both doctors and (psychiatric) patients were concerned about confidentiality.

Table 5. Positive and negative experiences with PHR.

Cancer patients

Positive views/reasons for using PHR:

'I feel more involved' (Drury 1996, Lecouturier *et al.* 2002)

'It works as an aide memoir' (Williams *et al.* 2001, Lecouturier *et al.* 2002)

'It informs health care staff of what happened' (Williams *et al.* 2001)

'It avoids the repetition of explaining events to every new professional I encounter' (Lecouturier *et al.* 2002)

Negative views/reasons for not using PHR:

'I am afraid that the PHR will result in additional workload for my doctor' (Drury 1996)

'I did not use it, because I did not want to burden staff with it' (Williams *et al.* 2001, Lecouturier *et al.* 2002)

'I forgot to take it to the doctor' (Williams *et al.* 2001)

'I was unaware that it had to be presented to the doctor' (Lecouturier *et al.* 2002)

'I felt discouraged by a previous lack of staff interest in the PHR' (Lecouturier *et al.* 2002)

'I don't want an additional responsibility' (Cornbleet *et al.* 2002)

'It is too much of an imposition at times of stress' (Cornbleet *et al.* 2002)

Psychiatric patients

Positive views/reasons for using PHR:

'It contributes as a communication channel and helps me to ask my physician questions' (Dijkstra *et al.* 2002)

Negative views/reasons for not using PHR:

'I did not use it, because I did not want to burden staff with it' (Lester *et al.* 2003)

'I forgot' (Lester *et al.* 2003)

'It is too personal' (Lester *et al.* 2003)

'Keeping the booklet is burdensome' (Lester *et al.* 2003)

Diabetes patients

Positive views/reasons for using PHR:

'The passport is useful for others, mainly when travelling or outside surgery hours' (Dijkstra *et al.* 2002)

'It is a tool to get more insight in my treatment' (Dijkstra *et al.* 2002)

Negative views

'It reminds me constantly of being ill' (Dijkstra *et al.* 2002)

'I expect a negative attitude from health professionals' (Dijkstra *et al.* 2002)

Physicians

Positive views/reasons for using PHR:

'It facilitates communication between professional s' (Williams *et al.* 2001)

'It helps the patient as an aide memoir' (Williams *et al.* 2001)

Negative views/reasons for not using PHR:

'It increases paperwork' (Drury 1996, Cornbleet *et al.* 2002, Dijkstra *et al.* 2002, Lecouturier *et al.* 2002)

'Lack of time' (Drury 1996, Cornbleet *et al.* 2002, Dijkstra *et al.* 2002, Lecouturier *et al.* 2002)

'It may increase ligation claims' (Williams *et al.* 2001)

'It may increase patient anxiety' (Williams *et al.* 2001)

'The PHR might be incomplete and therefore unreliable' (Cornbleet *et al.* 2002)

'I am concerned about confidentiality' (Cornbleet *et al.* 2002, Williams *et al.* 2001)

'It doesn't contribute anything new' (Dijkstra *et al.* 2002)

DISCUSSION

Our most important finding is that we found no studies about undocumented immigrants and PHRs. All results in this review are from patients other than undocumented immigrants. Therefore, our results are not direct0ly applicable to the group of undocumented immigrants. The studies we included concerned patients with cancer, psychiatric patients and diabetes patients. In order to draw conclusions we have to focus on similarities and differences between these patient groups and the undocumented immigrants. How undocumented immigrants would access the services to obtain a PHR in the first place is not studied in this review, but obviously needs attention as well.

In most cases patients keep the PHR in good order. Especially among patients with cancer, almost no loss was reported. For patients with long-term mental illness, the figures are less positive. This can be explained by a longer follow-up period (one year vs. three or six months) but it is more likely that in this vulnerable patient category of patients, problems like motivation and limited organisational abilities play an important role. Furthermore, confidentiality of the medical record information can make them more cautious towards using the PHR. Nevertheless, the majority of psychiatric patients still had their PHR after one year.

Since for undocumented immigrants the PHR is often the only available record, it might be even more important to keep than for patients with cancer or psychiatric patients. However, confidentiality of the medical record and personal information is for this group most likely even more important, and lack of trust can result in reluctance in certain situations.

The use by patients of the PHR is very high among patients with cancer.

Information and communication among professionals and between professionals and patients is important in the specific care for these patients with cancer. An

adequately informed physician is better positioned to give appropriate care. The serious medical problems among patients with cancer make the availability of a PHR more essential. This probably stimulates the usage.

The need for information and communication between professionals is also very high in the group of undocumented immigrants, as patients often have no regular GP and medical record information is usually not available. Communication and information between professionals and with the patient is often fairly unsatisfactory.

The frequent changes in addresses and physicians make it even more difficult. Continuity of care is limited. Therefore, adequate help for medical problems is often beyond reach for undocumented immigrants. This may increase the motivation for undocumented patients to use a PHR.

Many of the positive views mentioned by the patients in the studies are applicable to undocumented immigrants. Patients feel more involved with the PHR, it informs health care staff and many of them mention that it facilitates communication with the physician. However, there may be problems. The use of the PHRs by physicians in the studies is lower than the use by patients, though use of the PHR by physicians of patients with cancer is still relatively high. The lower use of the PHR by physicians of mentally ill patients can be explained by the lower use by the patients themselves.

Mentally ill patients often lose their PHR and use it less frequently in comparison to patients with cancer. Keeping the booklet is a burden for some of them, and they report that they sometimes forget to bring it to their physician. Therefore, physicians of mentally ill patients were confronted infrequently with a PHR and this may affect motivation. The PHR is only useful for a physician if it is complete and reliable.

Contrarily, undocumented immigrants might keep and use the PHR more systematically, because of the importance to them.

Another possible threat is the concern of many physicians of an increase in

paperwork and therefore a lack of time. For physicians, double administration is a drawback connected to the PHR. However, in the medical care for undocumented immigrants, in most cases there is no alternative record. Therefore, in most cases the PHR will be at least 'time neutral', but most likely it will save time because it provides the doctor with essential information about the patients' history and medication.

Though our results are not directly applicable to the group of undocumented immigrants, there are arguments that a PHR for this group of patients is appropriate for improving the continuity of care and thus quality of care for undocumented immigrants. However, the uncertainty of our findings is considerable. We need to know if undocumented immigrants are motivated to use the PHR, if language barriers are important and what the importance of confidentiality is. Furthermore, if the PHR for physicians of undocumented immigrants is indeed beneficial and timesaving and cost-saving. These questions need to be answered prior to investigating operational feasibility. Therefore, a qualitative approach might be useful to solicit the views of undocumented immigrants and health care professionals.

In addition, we recommend a pilot evaluation of the use of PHRs for undocumented immigrants.

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Chapter 8

Patient-held records for undocumented immigrants: not the panacea to improve continuity of care

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ABSTRACT

Objectives To assess the use and acceptability of a patient-held record (PHR) for undocumented immigrants.

Methods Explorative design with structured interviews and focus group discussions. Undocumented women in the Netherlands > 18 years of age were provided with a PHR After 3-4 months women were asked about the use of the PHR and the PHR was checked for new entries. Simultaneously, a questionnaire was mailed to the GPs. Attitudes towards the PHR were explored in focus group discussions.

Results The use of the PHR was low. Women who were not registered with a GP used the PHR more frequently (55%) than women who were registered (32%). If women were registered, both women and GPs considered it redundant. GPs expressed that the additional time investment is a problem.

Conclusions Countrywide general introduction of the PHR is not recommended. The use of a PHR by undocumented women and their doctors is low. A possible explanation is that we considered a solution for theoretically a striking problem in medical practice, not a solution for problems as felt by undocumented women or GP's.

Keywords

Illegal immigrants, Undocumented immigrants, Patient-Held Medical Records, Medical Records, Quality of Health Care, Continuity of Care

INTRODUCTION

An estimated number of 175,000- 180,000 undocumented immigrants live in the Netherlands, 25,000-50,000 of them are women.[1] Undocumented female immigrants in the western world experience poorer health and report substantially more health problems compared to other migrant groups in the host societies.[2;3] Health problems are related to their past and present situation. [3-8] Therefore, adequate health care is necessary. Unfortunately access to health facilities is problematic for undocumented immigrants in the Netherlands and many other Western countries.[2;9-14] Moreover, physicians experience serious problems in providing proper care as a result of communication problems, the complexity of morbidities, and the extra workload. Furthermore, past and actual record information are often not available.[15] As a consequence continuity of care for undocumented immigrants is worrisome. This is likely to influence the quality and cost of care.[16;17] Knowledge of a patient's medical history is a substantial contributor to saving time, referrals, and reduction in the use of medication.[18] Moreover, knowing the patient's medical history improves health outcomes.[19]

In the Netherlands, all regular residents are obliged to accept health insurance, but since 1998 a law prohibits undocumented immigrants from obtaining this coverage.[20] Undocumented immigrants, however, are entitled to receive all "medically necessary care," which is defined as responsible and appropriate medical care as indicated by the treating doctor.[21] In the Netherlands, nearly all inhabitants are registered with a GP; the GP administers all first-line care, makes required referrals to specialist care, and coordinates other health services when needed. It is government policy that undocumented immigrants are supposed to visit a GP for health care problems. Therefore, lacking medical record information is especially a problem for GPs.

In theory, patient-held records (PHRs) are a solution for this problem and can be valuable for physicians worldwide. In the Netherlands, Médicins du Monde is

considering the widespread implementation of PHRs for undocumented immigrants.[22] However, until now no studies have been published regarding undocumented immigrants and PHRs. Studies about PHRs for other vulnerable patient groups, such as psychiatric and cancer patients have generally been positive. [23] In the medical care for undocumented immigrants, there is often no alternative record. Thus, a PHR will likely save time since it can provide the doctor with essential information about the patient's history and medication. Further a PHR for undocumented immigrants could improve the continuity of care, and thus the quality of care. However, the uncertainty of the appropriateness is considerable. Therefore, we decided to conduct an exploratory study to assess the use and acceptability of a PHR for undocumented immigrants and GPs.

METHODS

Research among undocumented women, especially among those that are not in contact with health care institutions, faces some methodological problems. Recruitment through usual channels, e.g. GPs is not possible because many undocumented women are not registered in a GPs practice or in any other place. Recruiting this group is time consuming and difficult as they live in a permanent threat of being arrested by the police and therefore hide in society. Gathering a representative sample is also not possible as these undocumented women are nowhere registered. Therefore we opted for an exploratory study with mixed methods, including 100 undocumented women. Obtaining quantitative and qualitative data at the same time was efficient and implicated minimum inconvenience for the participants. Secondly it provides a better understanding of the problem. [24]

Study population

The study population consisted of 100 undocumented women ≥ 18 years of age living in different parts of the Netherlands, participating in a larger project that aimed to evaluate the health status of undocumented immigrant women and the obstacles they experience to access health care.[3;13;25] The women were recruited with the help of voluntary support organisations, GPs, midwives, and churches. To include women not yet identified by health professionals or an organization, advertisements were placed in local newspapers and recruiting posters were placed in locations frequented by immigrants. Further we made use of snowball sampling: we asked participants with whom contact had been established to refer us to other females who could potentially participate.

Diversity was sought according to age, country of origin, and reason for being undocumented. Undocumented women that showed interest to participate received an explanatory letter in their own language. The research assistant contacted all candidates by telephone. During this phone call, additional information was provided to the women or a relative. If she agreed to participate, an appointment was made. Information about the identity of the sponsors (among others, the Dutch Ministry of Social Affairs and Employment), was not provided. Primarily in order not to deter participants, but to avoid bias, the participants were explicitly informed that participation could not lead to a residence permit.

The record

The PHR used in the study was developed by an expert panel and was designed for adult undocumented immigrants. It was designed for use by one individual only. An A5 size, soft, covered booklet in a transparent cover provided space to insert additional leaflets, test results, and appointment cards. It contained separate sections for personal details, medical history, chronic diseases, medications, and allergies. Space was created for free text entries by health

professionals, details of earlier pregnancies, results from blood tests, and useful addresses and telephone numbers.

Study design and data collection

Participants were provided with a PHR after history-taking and a purposive physical examination by the first author, a registered GP. Medical and personal data were entered in the PHR. If necessary, interpretation during history-taking was offered. Socio-demographic information was obtained and included nationality, marital status, children, housing conditions, occupation, education, duration of residence in the Netherlands, and reason for staying in the Netherlands.

Participants received instructions about the use of the PHR from the research assistant. The women were instructed to present their PHR to medical professionals whenever consulting someone in the future. A letter was mailed to every patient's GP, outlining the purpose of the record and asking for their cooperation. Additionally, the GPs were informed about the findings of the history-taking and physical examination. Forty-four women were not registered with a GP. The research assistant helped those women to find a GP and subsequently she mailed the information about the PHR and history taking and physical examination to this GP.

After 3-4 months, the research assistant approached the women again to make an appointment and asked them to bring the PHR. Respondents were provided with a questionnaire about the use of the PHR and the PHR was checked for new entries.

The use of the PHR by the GPs of the women participating in the study was evaluated through a questionnaire that required minimal time for them to complete, in order to ensure a satisfactory response. Questions concerned the use of and experience with the PHR. When applicable, the research assistant

mailed a reminder. If there was still no response to the questionnaire, the research assistant contacted the administrative assistant of the GP by telephone.
Additionally, two focus group discussions with undocumented women and two focus group discussions with GPs were conducted by independent moderators to explore attitudes towards the PHR. All women participating in the study that understood and spoke Dutch sufficiently were invited to attend these focus group discussions. For the focus group with GPs we approached 13 GPs practising in deprived areas in Nijmegen and Rotterdam with experience in the care for undocumented immigrants. The topic guides were developed by an expert panel. Group discussions lasted 1 hour, were recorded on audiotape, and transcribed by the research assistant. Both the first author and the research assistant observed the group discussions, took field notes, and described non-verbal reactions.
Approval from the study was obtained from the Radboud University Nijmegen Medical Centre Ethical Committee (nr: CMO 2005/204).

Data analysis

The quantitative data from the interviews and the questionnaire were analysed using SPSS for Windows (version 16.0, SPSS, Inc., Chicago, IL, USA). Two-tailed Pearson chi-square tests were used to examine the relationship between being or not being registered with a GP and using and keeping the PHR.
Two authors (MS and MvdM) independently analysed the qualitative data. After familiarisation with the data, the researchers carried out thematic analyses to identify and categorize major themes and subthemes. The notes, field notes, and transcripts were independently coded and subsequently the researchers jointly defined the most important themes. In case of disagreement, both researchers tried to reach consensus by discussion. In case of a remaining dispute, the third author (ALJ) was consulted.

RESULTS

In order to reach our goal to include 100 cases, we approached 124 women thought to be eligible to participate in our study. Finally, 100 women participated in the study, all women accepted the PHR.

Follow-up interviews were conducted with 72 women; with 28 women we lost contact. In the same period two focus groups for women were conducted (one semi-urban [8 participants] and one metropolitan [11 participants]). All participants of the focus groups had an individual follow-up interview as well. The characteristics of the 100 patients who were originally included in the study, the 72 women who participated in the follow-up interviews, and the 19 women participating in the focus groups, are shown in Table 1. The women participating in the follow-up interviews were younger than the non-responders; the other demographic variables were comparable. Of the total study population, 44 % of the women were at the time of the first interview not yet registered with a GP; we succeeded in finding a GP for 32 of these 44 women.

We received 73 of the 88 questionnaires that we mailed back from GPs. Fifty-nine questionnaires contained information concerning undocumented patients and the PHR, 14 GPs claimed that the participant was not registered in their practice. In the same period, two focus groups for GPs were conducted (one semi-urban [5 participants] and one larger city [7 participants]). Seven GPs were males and five were females.

Table 1: Patient characteristics of study population and follow-up group: n(%)

General characteristics	Study population (n=100)	Follow-up (n=72)	Focus groups (n=19)
Mean Age, yr [a]	36,4	38,2	30,0
Partner			
Yes	53(53)	35 (49)	10(53)
No	47(47)	37(51)	9(47)
Having children			
Yes	73(73)	54(75)	14(74)
No	27(27)	18(25)	5(26)
Country of origin			
Eastern Europe/former USSR	30(30)	21 (29)	9(47)
Sub Sahara Africa	21(21)	13(18)	0
Turkey/Middle East/North Africa	12(12)	10(14)	4(21)
China/Mongolia	12(12)	9 (13)	2(11)
Afghanistan/Iran	11(11)	7(10)	0
Middle and South America/ Philippines	8(8)	7(10)	1 (5)
Surinam	6(6)	5(7)	3(16)
Reason to come to Netherlands			
Political reasons	58(58)	41(57)	10 (53)
Non-political reasons:	42(42)	31(43)	9(47)
Economic reasons	14(14)	11(15)	1(5)
Personal reasons	29(29)	20 (28)	8(42)
Employment status			
Unemployed	79(79)	59(82)	15(79)
Student	1(1)	0	0
Full time or part-time job	20(20)	13 (18)	4(21)
Housing			
Semi permanent residence	24(24)	16(22)	5(26)
Temporary residence	69(69)	52(72)	13 (68)
Homeless	7(7)	4(6)	1 (5)
Literacy			
Able to read and write	81(81)	59(82)	19 (100)
Difficulties with reading and writing	8(8)	5(7)	0
Illiterate	11(11)	8(11)	0

[a] 1 missing, did not know age

Patient use of the PHR

Since the first contact, 72% (51) of the women (n=72) visited a GP and 41% (21) of them brought the PHR to the appointment (Table 2). Reasons for not taking the PHR to the GP or another health professional included the following: PHR is not needed because data are already in the computer (6), loss of the

booklet (4), forgot the PHR (4), lack of understanding of the purpose (4), and doctor is not interested (3). In non- GP encounters, patients brought the PHR even less frequently to the clinician (16%).

Table 2: Patients use of PHR after 3-4 months in percentages (n)

	n (%)
Interview (N=72)	
Still in possession of the PHR	61 (85)
Had contact with GP	51(72)
Took PHR to appointment	21(41)
Gave PHR to GP	19(37)
Had contact with other health professional	37(52)
Gave PHR to health professional	6 (16)
Inspection of PHR (N=65)	
Inspection of PHR possible	46(64)
PHR in good state	42 (91)
PHR in moderate state	4 (9)
Patients with new entries in PHR	10 (22)
New entries (n=18)	
Entries made by GP	7 (39)
Entries made by practice nurse	4 (22)
Entries made by dentist	3(17)
Entries made by physiotherapist	2 (11)
Entries made by socially worker	2(11)
Future use[a](N=72)	
Want to use PHR in the future	54 (82)
No plans to use PHR in the future	7(11)
Don't know yet	5(8)

[a]6 missing

Table 3 shows the differences in use of the PHR between women who were and were not registered with a GP. Undocumented women who were initially not registered with a GP showed their PHR more often (55%) in comparison to those who were registered previously (32%). The GPs of women that were initially not registered also made more entries in the booklet (30% vs. 6%).

Table 3 Usage of PHR in follow-up patients registered with a GP compared to follow-up patients not registered with a family physician in percentages (n)

	Registered N=43	Not registered N=29	p-value
Still in possession of PHR	79 (34)	93 (27)	p=0.105
Had appointment with GP	31	20	
Took PHR to appointment	32 (10)	55 (11)	p=0.107
Gave PHR to GP	26 (8)	55(11)	p=0,012*
GP made new entries	6 (2)	30 (6)	p=0.015*

GPs use of the record

Fifty-eight percent (34) of the 59 GPs reported that they had at least one appointment with an undocumented patient. They reported that only 24% of the 34 women showed the PHR to them. If the women showed their PHR, 88% of the GPs reported that they looked in it. Twenty-five percent of the GPs reported that they made new entries in the PHR and 25% of the GPs could not remember their action.

Patients views of the record

Many women in the focus groups mentioned that they did not need the booklet because they were registered with a GP that had their medical history in the computer.

> *"I am registered with a GP. I am satisfied. In fact all my data are in her computer….."*

Several women felt embarrassed to present the booklet to the physician because they did not want to burden the physician or because they felt it as a token of lack of confidence in the doctor.

> *"If I bring it to the doctor, she will believe that I don't trust her."*

Some women stated that their physician was not willing to use it.

> *"I want to use it but I don't succeed."*

Confidentiality was a problem for several women in the focus groups. These women were concerned that they might lose the booklet.

> *"It is quite confidential; my name and other things are in it. I use it when I have to go to the doctor, but I won't keep it in my handbag. You can say in one word: fear……."*

In the focus groups, several women expressed that they appreciated the booklet mainly for future use abroad or in an unstable situation. Other women stressed that they would have preferred to have a PHR for their children, because it would have greater importance for them.

GPs views of the record

Many GPs expressed that the time investment is a problem.

> *"The problem is that with undocumented patients you have already more administrative fuss. More diagnostics, more actions……, so everything that comes additional…… "*

Some of them were prepared to make concise entries from the consultations, but no GP was willing to enter all personal particulars and full medical history for the initial set-up of the PHR.

Several GPs mentioned that a PHR is redundant for undocumented immigrants registered with them since they entered these patients in their regular computer system.

> *"If the migrant is registered with a GP it is not necessary. If they visit different physicians in different places it can be useful."*

GPs emphasized that the PHR is only valuable if patients bring in the document each time and doctors make relevant entries at each visit.

DISCUSSION

The results of this exploratory study show that the use of the PHR by undocumented immigrants is low. Less than one-half of the women show the PHR to health care workers. Among women who are not registered with a GP the use of the PHR is significantly better, but still dissatisfactory. The use of the PHR in our study population was less in comparison to other vulnerable patient groups. [26-31]

If women were registered with a GP both women and GPs considered a patient-held record redundant. Another important reason for not using the PHR that women reported, was the fear to upset and burden the doctors. Undocumented women appear to negotiate with great care all their relationships with country representatives in order not to upset them and provoke retaliation.[13] This applies possibly also to us as researchers. Most likely, some experiences and opinions remained unmentioned. For example concerns about a possible misuse of information by doctors as expressed by many Western patients.[32] It is important to take this into consideration in the interpretation of the results. The benefits of a PHR for undocumented immigrants may even be smaller than the results of this study suggest.

The fear of undocumented women to burden doctors seems realistic. GPs are concerned for an increase of paperwork because of the PHR and they stress that they do not have the extra time to make and keep the booklet up-to-date. The concern for an increase of paperwork and therefore a lack of time was reported by physicians of psychiatric and cancer patients as well.[26-28;31;33]

Our study has some limitations. The follow-up period was relatively short; some women had not yet visited a health professional. We deliberately choose a short follow-up period to minimize recall bias, but also because undocumented immigrants frequently change residence. For the qualitative data the focus group discussions ideally should have been conducted in the women's own language with a moderator of her own culture. Unfortunately, because of the diversity in

origin this approach was not feasible. This made in-depth conversations more difficult.

The strength of the study is that undocumented immigrants themselves were interviewed. Policymaking for this group is often done without collecting and considering the opinions of undocumented immigrants themselves. Therefore this study contributes important information.

We conclude that countrywide general introduction of the PHR is not recommended. Usage in both GPs and undocumented women is low. A possible explanation is that we considered a theoretical solution for a management problem in medical practice, not a solution for a problem as felt by undocumented women nor for problems as felt by GPs. We hypothesized that a PHR could empower undocumented women, make work for GPs easier and improve the quality of health care provided to undocumented immigrants. However, we failed to inventory problems and opinions of patients as well as health care workers. This is an important pitfall especially in vulnerable groups like these women, who are not used to speak up for themselves. The lesson we learned is that it is of paramount importance when thinking about interventions to improve quality of care to consult first the opinions of all actors.

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Chapter 9

General Discussion

GENERAL DISCUSSION

Overview of the study

In the previous chapters we presented the results regarding the health status of undocumented female immigrants in the Netherlands, their problems in accessing health care facilities and the acceptability of a patient-held record in General Practice. In this last chapter we will discuss our main findings and connect the separate studies. We will discuss implications and recommendations. Finally we will formulate a conclusion.

HEALTH STATUS

Perceived health

Undocumented women in our study perceive their health as very poor. Consequently, we conclude that their health status is vulnerable.[1-4] Women usually perceive their health worse in comparison to men.[5-8] This can be explained by biological (e.g. genetic, hormonal), psychological (e.g. chronic stressors, gender images), behavioural and social factors (e.g. socio-economic status, gender-based violence).[9] Immigrants experience their health worse than autochthonous people do.[10-15] The "healthy immigrant effect" usually only exists in the first period after arrival in the host country.[16;17] The lower perceived health can be explained by an adverse socio economic status and social factors such as discrimination, culture and health seeking behaviour. Gender differences persist across different ethnic groups[15] : immigrant women perceive their health worse in comparison to male immigrants.

The undocumented women in our study rate their health considerably worse and have substantially more health problems than legal immigrant women.[15;18] A recently published study by Médecins du Monde among undocumented men and women that have been able to make contact with health services, shows that the perceived health of women is very poor in general, but better than we

found.[19] An explanation for this is that we included women that are unknown to health care services or support organizations.

The outcome of health perception as "very poor" confirms the particularly vulnerable health status of these women. Assuming that (illegal) migration requires a strong and healthy body and mind, a following undocumented status in the host country is a strong ill making factor. Explanations for this include the decreased access to health care facilities, permanent stress of being arrested by the police, exploitation by employers and inferior living conditions in comparison with legal immigrants.

Also gender differences have an important influence on the health status of undocumented immigrants.[20;21] Gender is one of the dimensions, like ethnicity and social class that form the basis of social inequalities of health.[22] The position of undocumented women in society is influenced by gender aspects. Gender roles in most countries lead to the expectation that women serve as direct caregivers to their children.[20;21] They have the responsibility of ensuring that their children are secure and get food and other resources. For undocumented women, this is equally true even though they are in a situation where they usually do not have the means of earning money and that are in a permanent insecure situation. This can have health consequences, since they experience more imminent priorities than their own health. Several women in our study report that the well- being of their children is their most serious concern. This may lead to ignorance of their own health problems.

The conclusion that having an illegal status is an additional ill making factor for women is an important supplement to the existing limited data on health problems and health needs of undocumented female immigrants. It stresses the importance of addressing this group of patients as a group with specific risks.

Health problems

Undocumented women report a very high number of currently existing health problems per women (11.2). This figure is almost the threefold of the number of problems reported by autochthonous populations and almost twice the number of problems that legal immigrant women report on a similar list of common complaints in the Dutch survey of general practice.[18;23] Chronic conditions are reported in comparable numbers as by autochthonous residents and immigrants with legal status. Besides more complaints related to chronic stress the most obvious explanation for the high number of existing health problems is the limited access and use of health care services by undocumented women. Health problems are not addressed and remain existent. This may lead to a further deterioration of their health status and lead to other health problems. For health care workers it is important to realise that if they meet undocumented women in their consultation rooms, these women may have multiple longstanding health problems. Probably they haven't seen a clinician for a long time.

Just like other patients, undocumented women will not always mention all health problems spontaneously. There is a gap between health problems assessed by an open-ended question, "Which health problems do you experience at this moment?" and problems reported when specifically asked for in a structured questionnaire. However, in this particular patient group it concerns longstanding, serious complaints like loss of weight, fatigue, lower abdominal pains, vaginal discharge, anxiety and agitation. Especially sexual and gynaecological problems and psychosocial problems are not disclosed. Possibly immigrant women do not realize that GP's also address psychosocial problems or they are ashamed of bring these up. For many women sexual and gynaecological problems are presented with extreme reluctance.[24] In particular when women are accompanied by their partners or family members they will not disclose these problems. Shame, hesitation to burden the doctor and careful negotiation with health care workers in order not to upset them, may play a role

as well. This may lead to a serious delay in the treatment of for example sexual transmitted diseases, leading to infertility and/or spreading of the infection, but also of psychiatric diseases. Untreated depression or PTSS may have serious consequences as well, including substance abuse, problems with children, relation problems, aggression, self neglect and even suicide.[25] Therefore, doctors should actively ask for especially sexual, gynaecological and psychiatric problems when they see undocumented women in their consultation room.

SEXUAL AND REPRODUCTIVE HEALTH

Sexual violence

We found very high percentages of sexual and physical violence. Undocumented women are at risk to experience violence both before and after entering the host country.[19-21] Comparisons with legal immigrants are difficult as representative studies are lacking. Among asylum seekers and refugees exposure to sexual violence is frequently mentioned.[26;27]

We have reasons to believe that undocumented women have an added risk to experience sexual violence. Undocumented women are more often in a dependent position and perpetrators know that they are afraid to go to the police to report the crime. The precariousness of the labour market for undocumented female immigrants means that they are more prone to violence and sexual harassment since they depend on their employers to retain their job.[21] Undocumented women are more often victims of human trafficking[28]and also prostitution is common, as it sometimes is the only way to earn some money.[19] Finally, as occurring among regular immigrants, intimate partner violence may increase with the time elapses since immigration.[29]

Most likely, the prevalence of sexual violence is even higher as the 28% reported in our study. Immigrants usually underreport this kind of violence, due to shame and fear to damage the family honour.[24] In view of the important health implications we recommend routine screening for exposure to violence.

Gender based violence is a strong risk factor for physical and mental health.[30-33] For physicians it is important to realize that a women often will not disclose violence if she is accompanied by another person.[34]

GP's and other health care workers should be aware that undocumented women are more at risk for HIV and other Sexually Transmitted Diseases (STD's). Only 19% of the women in our study were completely screened for STD's, only 28% for HIV and only 15% had at least one PAP smear performed during their life. This requires an active role of health care workers if they see undocumented women in their consultation rooms. When GP's do screen undocumented immigrants the percentages of positive tests turn out to be strikingly high. [35]

Use of contraception, abortion and pregnancy care

In comparison to regular immigrants, abortion rates are high,[36-38] use of contraception is low and there is a high prevalence of lacking or delayed pregnancy care.

Many of these women are dependent from their male partners, support organization, employers and others, to control their reproductive and sexual choices. They cannot decide for themselves whether to have sex or not, whether to use contraception or not, whether to carry the pregnancy or have an abortion. According to art 12 of the United Nations international bill of rights for women[39] and the definition of health by the WHO,[40] women should have the freedom to decide if, when and how often to become pregnant.[41] Undocumented women in the Netherlands often do not have that freedom. They should be empowered to obtain that freedom.

HEALTH CARE UTILISATION

Health care utilization by undocumented women in our study appears to be less in comparison to legal immigrant women and female asylum seekers/refugees in the Netherlands.[15;23] Yet, they report almost twice the amount of health problems

in comparison to legal immigrant women in the Netherlands. The vast majority of the women in our study report problems regarding access to health care and unmet health needs. After analysing experiences in accessing health care, we conclude that (access to) health care for undocumented women is variable and unpredictable. Primarily it depends of the health care provider they encounter. Further, identified non-institutional obstacles are strongly related to the position of undocumented women in society.

Institutional obstacles

Despite the fact that the Dutch government aims at equal access to health services and doctors are obliged to provide appropriate and responsible care to undocumented immigrants,[42] access to adequate health care is not always obvious. Undocumented women are dependent of individual healthcare workers to obtain required healthcare. Fortunately, many health care workers will provide care, especially in primary care only a few problems were reported, but for the undocumented immigrant it remains unpredictable. Health care workers do not always act in accordance with rules of conduct. Rejection of undocumented women by GP's and specialists, discrimination through health care providers by providing different/substandard care compared to legal patients (e.g. treatment in corridor instead of consultation room), neglect (e.g. no further check-ups after treatment for breast cancer) , cancellation of surgeries and unjustifiable invoices, all these things happen and are reported by the women. These phenomena are also reported in other studies.[19;43-50]

Explanations for this include inadequate information about legislation concerning health care for undocumented immigrants as was also reported in other studies[43;44;51;52] Although most health care workers in the Netherlands received written information and relevant electronic information is easily accessible,[53] health care providers are not always aware of the fact that they are obliged to provide care to undocumented immigrants. Furthermore, they are not

always informed about the procedures for reimbursement of costs. Attitude and prejudice in relation to undocumented immigrants are also relevant.[54]

Positional obstacles

Undocumented women have a marginalized position in our society. For food, shelter, safety and also healthcare they are dependent on helpful reliable individuals. A good relation is crucial. The precarious migratory status of the women may push them to negotiate with great care all their relations with host country representatives. In most cases safety is prevailing above health.

Undocumented women will prudently address health care professionals. Negative experiences with government institutions, employers, landlords and also other health care workers enforce their prudence. Our study shows that they have reasons to do so. The women appear very worried to upset and burden health care workers.

Fear for deportation make them refrain from seeing a doctor[19;48;55] or being very precarious choosing one. Women who find access to a health care facility generally succeed with help of a trusted person e.g. a family member or a person working for a support organisation.[44;56] We are aware that a small group of GP's in the Netherlands provides care to a vast majority of undocumented patients.[57]

Not only fear for deportation, also shame and guilt make women refrain from seeking care. Again this is influenced by the assumed precarious relation with health care workers. The assumed precarious relation also causes that they will not mention all their problems to a doctor.

In this thesis differences in health care utilisation between different groups of undocumented female immigrants are large. Rejected asylum seekers have more contacts with health care workers and are more often registered with a GP than other groups of undocumented immigrants. An explanation for this is that they became familiar with the Dutch health care system during their stay in the asylum seekers centres and that they have more contacts with "trusted persons"

from voluntary support organisations. In our study voluntary support organisations prove to be very important to assist undocumented immigrants to access health care in the Netherlands. Voluntary support organisations could play an important role in identifying other groups of undocumented immigrants and assist them to access health care.

On the other hand support organisations should realise the fragility of their relationship with undocumented immigrants and address them prudently. Interference of support organisations in our study sometimes results in violation of privacy and then becomes an obstacle in accessing health care. For example women in our study report that volunteers act as a triage filter between the undocumented women and the GP. Women are asked to explain their health problems in detail and volunteers than decide whether or not to make an appointment with the GP. Sometimes they even accompanied them during the consultation. This was reported as undesirable in a limited Dutch study among undocumented men as well.[58] At the same time undocumented immigrants are dependent on organizations for housing, food and access to health care. This results in dependence and difficulties in making autonomous decisions.

Information shortage is an important factor for not accessing healthcare as well.[19] Undocumented persons are not informed about their rights and about the obligation of professional confidentiality in the Netherlands that prohibits doctors to report undocumented immigrants to immigration authorities.

Consequences

There are many untreated health problems in undocumented women. This implicates serious health risks for these women and their unborn children in the first place, but implicates risks for public health as well. Preventive screening rates for sexual transmitted diseases, HIV, hepatitis B and TB are low although undocumented immigrants have a higher incidence of TB, HIV, hepatitis B and

sexual transmitted diseases in comparison to the indigenous population in the Netherlands.[59-64]

Our study stresses that easy access to facilities where undocumented TB suspects can be diagnosed and treated, is not guaranteed. Women in our study with signs and symptoms of TB experience obstacles in access to health care or refrain from seeking help. Risks for public health could be considerably reduced when access to health facilities for undocumented immigrants would improve.

The danger of discussions about risk for public health from undocumented immigrants is that one might focus more on protecting the regular population than on improving the health of undocumented immigrants. Recently Achbar stated that publication of research results that imply that undocumented persons are more likely to transmit tuberculosis, could lead to further stigmatization of undocumented immigrants.[65] On the other hand, the results of their and our studies show that reduction of the barriers accessing health care could enhance TB control and benefit both undocumented immigrants and public health.[66]

PATIENT-HELD RECORDS

Before the start of the study we hypothesized, like other organizations [67] that implementation of patient-held records could be a strategy to empower undocumented women, make access to health care easier and improve the continuity of care.

However, this study shows that the use of patient-held records by undocumented women and GP's turns out to be low. Reasons for not using the PHR are hardly mentioned. We assume that they want to please us by approving the project, but do not use it because they do not want to burden the doctor and probably feel insecure with it. This is in line with our observation that women are very precarious in their contacts with all Dutch citizens.

Probably the patient-held record is not of much interest to them. They do not perceive benefits, however the PHR does require a secure place to put it away

and efforts to present it to the doctor. Probably most women do not understand the content and therefore distrust it. After food, shelter and security actual treatment of health problems is a first priority for undocumented women. The booklet is not considered helpful to that end.

We considered a solution for a theoretically striking problem in medical practice, not a solution for a problem as felt by undocumented women nor for the most important problems as felt by family physicians. We hypothesized that a PHR could empower undocumented women, make work for family physicians easier and improve the quality of health care provided to undocumented immigrants. However, we failed to inventory problems and opinions of patients and health care workers beforehand. This is an important pitfall for policymakers and health care professionals especially applicable to vulnerable groups like these women, persons that hardly speak up for themselves.

To improve health and health care utilization of undocumented women one should start from problems as experienced by the women. Solutions should come from the women themselves or should be considered from the perspective of the women.

REFLECTION OF THE METHODOLOGY

Our study is an exploratory study. It involves 100 women purposively recruited patients. Conclusions on numbers should be taken cautiously. However, we believe that the results contain important new information. Very few studies involve undocumented immigrants themselves. Several organizations and persons express the need for studies among undocumented immigrants in person.[50;68;69] As far as we are aware, this is the first study that also includes undocumented women that are not in contact with health care professionals or support organizations.

Recruiting and interviewing undocumented women prove very time consuming and difficult and require patience, understanding and creativity. We had to

accept that the research took other paths than usual and that we had to invent unusual and unconventional solutions. For example it turned out to be very difficult to recruit and interview undocumented women that came to the Netherlands to work as a domestic worker, a fairly large group in the Netherlands. These women usually work well over 12 hours per day. Therefore, we decided to interview them late in the evening.

Women often were afraid to come to the location of the interview. One day, by coincidence, a police car was parked in front of our interview location: a nursing home. None of the participants showed up. Furthermore, the research assistant made appointments with the women by telephone and phoned them again if they did not show up. Several women expressed that they feared entering the building were we held the interviews because they had no identification papers. Later we mailed all women an official invitation letter. This reduced "no-shows" considerably. Above all, explaining the study and obtaining true informed consent was time consuming. Sometimes two or three appointments were necessary to obtain true understanding of the study by the participants.

Because it was very difficult to gain the trust of the women, many were afraid of being arrested by the police, we decided, after careful consideration and consulting experts in the field, not to audiotape the interviews but to make notes. The interviews ideally should have been conducted in the women's own language by somebody of her own culture. In view of the diversity of countries of origin this approach was not feasible. We believe that the loss of valuable information by not audio taping is not very substantial and important, since part of the information we obtained from the women is factual material and the other part was written down during or direct after the interview.

Tracing the women again for the follow-up interviews was time-consuming and difficult again. Since undocumented women frequently change residence, many could not be reached at their original address. Most of them did not answer their mobile phone either. Therefore, we started to send them SMS messages. This

improved the response considerably. Afterwards women stated that they were afraid to answer a telephone call from an unknown number.

Although this thesis is unique since we intended and succeeded to include also "invisible" women, we could not fully achieve that objective. Finding illegal sex workers, undocumented labour immigrants and undocumented family members of legal immigrants was extremely difficult. These women avoid contacts with the Dutch society and are even more reserved with strangers than other undocumented women. Some women proved too afraid to participate in the study or did not show up. Therefore there is a group of undocumented women that still remains "invisible" and about which we have very little information. We have reasons to believe that their access to health care is even more problematic.

Probably because of the serious practical problems, very little research is done among undocumented women. As a consequence policymaking for this group is often done without collecting data from the undocumented immigrants themselves. Therefore our study adds important information on the health status and access to health care of undocumented women to the existing literature.

REFLECTION OF THE FINDINGS

Data about health care utilisation are most likely too optimistic. Rejected asylum seekers were overrepresented in our study and this study shows that these people have better access to health care facilities than for instance women that came to the Netherlands for personal or economic reasons.

Women were often accompanied by another person during the interview. This certainly influenced the outcomes of the study. Prevalence of gender based violence and "shameful" diseases and symptoms such as STD's or vaginal discharge are in reality most likely higher. We decided not to refuse these companions in order not to lose the trust of the women.

IMPLICATIONS AND RECOMMENDATIONS

Human rights

The right to health care, recognized by the UN international covenant on Economic, Social and Cultural rights,[52] is in fact not guaranteed in the Netherlands. In theory, undocumented immigrants in the Netherlands are entitled to receive all "medically necessary care", defined as responsible and appropriate medical care as indicated by the treating doctor.[42] In practice obtaining appropriate medical care is inconsistent and unpredictable and highly dependent of the attitude and willingness of the health professional to comply with rules. The Dutch government should make efforts to guarantee the right to health care for undocumented women. Health care providers need to be informed about existing legislation and explicitly instructed that they are obliged to provide care to these people.

Mediators

Health care utilization is low. Undocumented women hide in society and do not seek help. They are afraid to visit health care facilities. Undocumented women fear government officials and are prudent in all their contacts including health care workers, and they have good reasons to do so. Therefore, women use mediation of trusted contacts, like voluntary support persons or legal family members, to obtain access to health care.

To improve access it is most important that women are able to make contact with these trusted contacts. In our opinion these persons and organizations should be facilitated to carry out this mediation. Voluntary support organizations can be provided with addresses of eligible GP's, midwives, hospitals and pharmacies and with information about health care for undocumented immigrants. They could play an important role also for the "invisible" populations. They should make efforts to identify undocumented immigrants not yet in contact with health care institutions.

Registration of Undocumented patients in General Practice

The quality of stable relation with one GP and the trust associated may be more important than any administrative and organizational measure. Undocumented patients and GP's experience few problems in providing quality of care if patients are registered with a GP. A trustful relation with a GP will also make it easier for undocumented women to speak about health problems such as vaginal discharge, sexual problems and depression. Therefore we believe registration with a GP will be beneficial for undocumented women.

Contacts by undocumented immigrants with Dutch GP's mostly occur in the deprived areas of the big cities.[70] Some GP's in those areas have many undocumented immigrants as patient. This can become a large burden with also financial implications since GP's can only obtain a reimbursement of maximum 80% of the cost incurred. Because of the required experience and affinity with the target group, it is recommended to concentrate the care for undocumented immigrants to a limited number of GP's. Further, health care workers and patients could benefit from an expert team of GP's, medical specialists and psychologists/ psychiatrists for counselling and advice. We plea that GP's obtain full reimbursement of their costs.

Empowerment of women

There is an urgent need for empowerment of undocumented immigrants through information about the Dutch health system, their rights and existing legislations. But even more important is empowerment by the strengthening of personal skills. The methods and means how this empowerment can be achieved are crucial for possible success. This thesis shows that undocumented immigrants fear country representatives and are very precarious in all their contacts. Therefore it should be carefully considered how, by whom and where empowerment could be achieved. Group sessions in an unknown building with an unknown professional are very likely to fail.

We should learn from the failed PHR project and should start from problems as experienced by the undocumented women. Neither policymakers and health professionals, nor support organizations, but undocumented women should dictate the agenda. They should determine what they need and in which way their needs could be fulfilled. Aim of empowerment is to reduce vulnerability. In other vulnerable groups empowerment proves successful and results in education and strengthening of personal skills. These initiatives result in enhanced self-esteem, improved negotiating skills, and the ability to recognize, avoid en escape violence.[71]

CONCLUSION

Undocumented women have a poor health status and their health care utilization is low. Undocumented women hide in society and do not seek help. Furthermore, health care institutions are inadequately accessible.

Although they have a right to health care, undocumented women will and cannot not speak up for themselves. Therefore, their problems will be easily neglected. Undocumented women do not exist in official statistics, are not included in morbidity and mortality figures. Their health problems are as hidden as they are themselves. To guarantee health care is a responsibility of the society. Both policy makers and health care workers should start seeking undocumented hidden women, identify their health problems and give them a clear and loud voice.

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Summary

Undocumented female immigrants have a marginalized position in society. Undocumented female immigrants have no permission to stay in the country and no right to health care insurance, try to hide in society, live in permanent fear of being reported to the authorities, and often live in dependence of male partners or employers. Therefore, it is difficult for undocumented female immigrants to speak up. In this thesis we have attempted to give these women a voice.

In Chapter 1 the rationale and aims of the thesis are explained, and the methodological and ethical considerations and limitations of the study are extensively discussed.

There are approximately 75,000-185,000 immigrants without legal status living in the Netherlands, 25,000-50,000 of whom are female. This population constitutes one of the most vulnerable groups in our society. It is reasonable to expect that these conditions have a negative effect on their health status. For clinicians, it is important to have information about the health status and specific health problems of undocumented women in order to provide adequate care. Unfortunately, such information is lacking. Studies among undocumented women are scarce and include no information about the health status and health problems of the "invisible" women who are not in contact with health care facilities.

In the Netherlands, undocumented female immigrants are entitled to all medically-necessary care. Nevertheless, little information is available about actual access to health care facilities obtained from undocumented women. Several publications, researchers, professionals, and organizations expressed concern about the accessibility of health care services for undocumented

immigrants in Western countries, but information about the obstacles in accessing health care from undocumented women is scarce. Further, research-based information about the actual use of health care facilities by undocumented women is lacking.

Physicians experience serious problems in providing undocumented immigrants with proper care as a result of communication problems, the complexity of morbidities, and the extra workload. Furthermore, the lack of adequate medical records is a problem. In theory, patient-held records (PHRs) might be a solution for this last problem and can be valuable for many physicians and undocumented patients worldwide. However, the uncertainty of the appropriateness of a PHR for undocumented immigrants is considerable because studies about the use of PHRs by undocumented immigrants are lacking.

Against the background as described above, the following study aims were formulated:

- To gain insight into the health status of undocumented women in the Netherlands and into the specific somatic and psychosocial health problems they experience.
- To assess which reproductive health problems and needs exists among undocumented immigrant women and to determine if they are able to fulfil these needs.
- To retrieve health care utilization data and identify obstacles that influence health care utilization of undocumented women.
- To determine the suitability of a PHR for undocumented immigrants.

Research amongst undocumented women, especially when including women who are not in contact with health care institutions or support organizations, has methodological consequences. Because undocumented women are not systematically registered anywhere, gathering a statistically-sound representative sample is not possible. Including undocumented women who are

not in contact with health care institutions or voluntary support organizations means that recruitment must take place through unusual channels and requires careful consideration. Recruiting participants in this way is time-consuming and very difficult. Furthermore, after contact with undocumented women is established, trust should be gained and safety should be guaranteed.

We conducted an exploratory study involving 100 undocumented women with a maximum variety in sociodemographic factors. Undocumented women ≥ 18 years of age were purposively recruited through churches, voluntary support organisations, general practitioners (GPs), and midwives. To find women not yet identified by health professionals or an organisation, advertisements were placed in local newspapers and recruiting posters were placed in locations frequented by immigrants. Further, we asked participants with whom contact had been established to refer us to other females who could potentially participate. The interviews were held in the following locations: public and primary health institutions; a shelter home; a nursing home; and occasionally in the women's temporary shelter. These locations were kept secret (including mediators).

To provide a nuanced and comprehensive understanding of the reproductive health problems and needs of undocumented female immigrants, their obstacles in accessing health care facilities and the acceptability of a PHR, we applied the following methods: structured interviews; semi-structured interviews; and focus group discussions. Both undocumented women and their GPs were interviewed. Participating women were provided with a PHR after history-taking and a purposeful physical examination. Medical and personal data were entered in the PHR. The research assistant helped those women who were not yet registered with a GP to find one.

In Chapter 2 extensive background information, based on literature study, is provided on living circumstances of undocumented immigrants, demographic data, legislation on access to healthcare in different Western countries, and

human rights. Also, the demographic details and results of the physical examination of our research group are presented in this chapter.

Unfortunately, there is no objective and commonly accepted term for non-citizens who are residing in a country without official permission. The term illegal immigrant is often criticized. We chose to use the term "undocumented," as it is most commonly accepted and recommended by the Platform for International Cooperation on Undocumented Migrants (PICUM), despite its disadvantages.

Estimates suggest that there may be 30 million undocumented immigrants worldwide. It has been estimated that undocumented immigrants make up 4% of the population of the USA, while estimates for European countries are lower (1%-2% of the total population, except for some Mediterranean countries where the percentage is higher). The demographic background of undocumented immigrants differs between Western countries. In the Netherlands there are relatively large undocumented populations from Surinam, Turkey, and Morocco. The reasons for migration are economic, personal, or political. In the Netherlands labour immigrants constitute the largest group. These are persons that come to the Netherlands for economic reasons; they mainly live in the four largest cities (Amsterdam, Rotterdam, Utrecht, and the Hague). The women in this group are frequently trafficked and end-up working in the sex industry. Another large group of women works as domestic workers. A substantial group of undocumented women in the Netherlands are refugees. The undocumented women consist of many women, often with children, with traumatic experiences in the past and without a social network. A third group consists of women, mainly from Turkey, Morocco, and Surinam, who came to the Netherlands for personal reasons, such as family reunion and marriage.

The living conditions of undocumented female immigrants are precarious. Undocumented female immigrants have a low or unpredictable income, are confronted with abusive practices by landlords, and lack entitlement to social

housing. This generally results in poor housing conditions, including overcrowding, poor sanitary facilities, poor hygiene, absence of warm water, and cold and moist conditions. The working conditions are often also unfavourable, and include low wages, long working hours, exploitation, and unsafe working conditions. Furthermore, many female undocumented immigrants experience or have experienced physical assault or sexual violence. All of these circumstances may have serious health implications. Unfortunately, there is no research-based information on the specific health problems of this group.

The right to health care is a human right recognized by the UN international Covenant on Economic, Social, and Cultural rights. The European Union member states, the United States, and Canada ratified the right of everyone to access health care. Yet, laws and practices in many countries deviate from these obligations. Laws and regulations are heterogeneous. Some countries are highly restrictive and entitle undocumented immigrants to almost no rights or on a payment basis only, while other countries are more generous.

In **Chapter 3** the health situation and specific health problems of 100 undocumented women are described. The general perceptions of health were evaluated based on the following single-item question on self-rated health: "In general, is your health excellent, very good, good, moderate, or bad?" Health problems were assessed by the following open-ended question and a list of common health problems and chronic conditions:"Which health problems do you experience at the moment?".

We conclude that attention is needed for the vulnerable health situation of undocumented women in the Netherlands. Sixty-five percent of the interviewed women rated their health as "poor" (moderate or bad), and 91% spontaneously mentioned having current health problems. On average, women reported about 11 complaints from a list of 26 common health problems. Gynaecologic and psychological complaints were very prevalent, but seldom mentioned

spontaneously. Undocumented women may not present important symptoms to physicians when the physicians encounter them. Physicians should therefore actively and specifically enquire about psychological and gynaecologic symptoms. Special attention is required for undocumented pregnant immigrants because their health situation makes them particularly vulnerable. We recommend special training on the health problems of undocumented female immigrant patients for physicians.

In Chapter 4 we determine whether or not undocumented women are able to exercise control over their reproductive and sexual health through data regarding sexual violence, use of family planning methods, and abortion. Also, reproductive health problems are discussed in this chapter. We used a structured questionnaire.

We conclude that the reproductive health status of undocumented female immigrants in the Netherlands is worrisome. Our results show a lack of or delayed prenatal care, low use of contraception, high abortion rates, low rates of PAP smears and STD screening, and untreated sexual and gynaecologic problems. Undocumented female immigrants are not able to exercise control over their own reproductive and sexual health for the following reasons: lack of information about reproductive health services and contraception; problems with financing of services; sexual and physical violence; and fear of deportation.

Undocumented women do not have the freedom to decide if, when, or how often to become pregnant. These women should be empowered to gather that freedom through education and strengthening of personal skills. Further research is recommended to explore how empowerment can be achieved effectively in this specific group.

In **Chapter 5** we describe the access of undocumented women to facilities where Tuberculosis (TB) can be diagnosed and treated. The International Union against Tuberculosis and Lung disease recommends that health authorities should ensure easy access to facilities where undocumented TB suspects can be

diagnosed and treated without fear of being reported to the police. We conclude that this is not guaranteed in the Netherlands. Of undocumented women that reside in the Netherlands for economic or personal reasons, only 33% were screened at least once for tuberculosis. Several women with severe TB-related symptoms reported problems in accessing TB control facilities. We recommend exploring ways to offer TB screening to undocumented immigrants and increase their awareness of the risk of TB.

In **Chapter 6** the use of health services by undocumented women and the obstacles they experience in accessing health care is described. We used questionnaires and semi-structured interviews of the undocumented immigrant women.

Thus, health care utilization of undocumented women is low. Many undocumented women have unmet health care needs. Sixty-nine percent of the women report obstacles in accessing health care facilities. There is evidence that health care utilisation by the undocumented women in our study was lower than legal migrant women and female asylum seekers/refugees in the Netherlands. This applies particularly to women that came to the Netherlands for personal reasons, such as marriage and reunion with family or for economic reasons. Women who came to the Netherlands for political reasons, such as rejected asylum-seekers, used health care facilities more often. This can be partly explained by a better understanding of the Dutch health care system; during their stay in the asylum seekers centres, the women were entitled to regular health care and received information about the Dutch health care system. Also, their contacts with voluntary support organisations may contribute to this difference; these organisations play an important role in assisting undocumented immigrants to access health care in the Netherlands. Almost all women in our study who were registered with a GP found their GP with help of a voluntary support organization.

Many undocumented women refrain from seeking health care because of personal obstacles, such as shame, fear, and/or lack of information. We conclude that these women need to be identified and informed about their rights, the health care system, and the duty of professional confidentiality of doctors. Also, health care providers need to be informed about existing legislation and explicitly instructed that they are obliged to provide care to undocumented immigrants. Finally, institutional obstacles to access care should be removed since they strengthen reluctance to seek help.

Chapter 7 contains the results of a systematic literature review related to the potential benefits of a PHR for undocumented immigrants. No studies were found about undocumented immigrants and PHRs. Therefore, we decided to eliminate two search terms (illegal and undocumented immigrants), and perform a broader search about the use of PHRs in general. This search yielded 61 articles, and 42 articles were excluded. Sixteen articles were screened for methodologic quality, seven of which met the criteria.

In these studies the use and appreciation of PHRs by patients was satisfactory. However, the results were not directly applicable to the group of undocumented immigrants. The studies we included concerned patients with cancer, psychiatric disorders, and diabetes. We therefore decided to do a pilot study about the use of PHRs for undocumented immigrants.

In **Chapter 8** we present the results of structured interviews and focus group discussions investigating the use and acceptability of a PHR for undocumented immigrants.

The undocumented women in our study were provided with a PHR. After 3-4 months, the undocumented women were asked about the use of the PHR and the PHR was checked for new entries. Simultaneously, a questionnaire was mailed to the GPs. Attitudes towards the PHR were explored in focus group discussions among undocumented immigrant women and among GP's.

The use of PHRs by undocumented immigrants was low. Less than one-half of the women showed the PHR to health care workers. Among women who were not registered with a GP, the use of the PHR was significantly better, but still unsatisfactory. If women were registered with a GP, both the women and GP considered a PHR redundant. Another important reason that women reported for not using the PHR was the fear to upset and burden the doctors. The fear of undocumented women to burden doctors seems realistic. GPs are concerned for an increase of paperwork because of the PHR and they stress that they do not have extra time to make and keep the booklet up-to-date.

We conclude that countrywide general introduction of the PHR is not recommended.

In Chapter 9 we discuss our main findings and connected the separate studies. We discussed the implications and recommendations. Finally, we formulated a conclusion.

Having undocumented status is an additional risk factor for illness in women, and highlight the importance of addressing this group of patients as a group with specific risks. Undocumented women report a very high number of currently existing health problems. Undocumented women will not always mention all health problems spontaneously. Indeed, sexual, gynaecologic, and psychosocial problems are not disclosed. When women were accompanied by their partners or family members, they did not disclose these problems. Doctors should actively ask for sexual, gynaecologic, and psychiatric problems when they see undocumented women in their consultation room.

Health care utilization of undocumented women is low. Access to health care for undocumented women is variable and unpredictable. It primarily depends on the health care provider that they encounter. Further, non-institutional obstacles are strongly related to the position of undocumented women in society. Fear for deportation make them refrain from seeing a doctor or being very precarious choosing one. Undocumented women will prudently address health care

professionals. Negative experiences with government institutions, employers, landlords, and other health care workers enforce their prudence. Our study shows that they have reasons to do so.

Women who find access to a health care facility generally succeed with the help of a trusted person, such as a family member or a person working for a support organisation. To improve access to health care, it is most important that women are able to make contact with these trusted contacts. In our opinion, these persons and organizations should be facilitated to carry out this mediation.

There are many untreated health problems in undocumented women. This implies serious health risks for these women and their unborn children, but implies risks for public health as well. The danger of discussions about risk for public health from undocumented immigrants is that one might focus more on protecting the regular population than on improving the health of undocumented immigrants. Our study showed that reduction of the barriers accessing health care could enhance TB control and benefit both undocumented immigrants and public health.

Before the start of the study we hypothesized that implementation of PHRs could be a strategy to empower undocumented women, make access to health care easier, and improve the continuity of care. The booklet is not considered helpful to that end.

We considered a solution for a theoretically striking problem in medical practice, not a solution for a problem as perceived by undocumented women or for the most important problems as perceived by family physicians. This is an important pitfall in research, especially in vulnerable groups like these women who are not used to speak up for themselves. To improve health and health care utilization of undocumented women one should start from problems as experienced by the women. Solutions should come from the women themselves or should be considered from the perspective of the women.

Our study was an exploratory study and involved 100 women purposefully recruited patients. Conclusions on the numbers should be interpreted cautiously. However, we believe that the results contain important new information. Because of the serious practical problems, very little research is done among undocumented women. As a consequence, policymaking for this group is often done without collecting data from the undocumented immigrants.

Although this thesis is unique because we intended and succeeded to include "invisible" women, we could not fully achieve that objective. Finding undocumented sex workers, undocumented labour immigrants, and undocumented family members of legal immigrants was extremely difficult. Therefore, there is a group of undocumented women that remain "invisible" and about which we have very little information. We have reasons to believe that their access to health care is even more problematic.

Although undocumented women have a theoretical right to health care, this is in fact not guaranteed in the Netherlands. Obtaining appropriate medical care is inconsistent and unpredictable, and highly dependent on the attitude and willingness of the health professional to comply with rules. Undocumented women will and cannot speak up for themselves. Therefore, their problems will be easily neglected. Undocumented women do not exist in official statistics, and are not included in morbidity and mortality figures. Their health problems are as hidden as they are themselves. To guarantee health care is a responsibility of the society. Both policy makers and health care workers should start seeking undocumented women who are "Hiding and Seeking" and identify their health problems.

Samenvatting

Ongedocumenteerde vrouwen hebben een gemarginaliseerde positie in onze gemeenschap. Ze hebben geen recht op verblijf in Nederland en ze kunnen zich niet verzekeren tegen ziektekosten. Ze zijn altijd op hun hoede. Ze zijn bang om in aanraking te komen met de politie of om aangegeven te worden. Vaak zijn ze in hun levensonderhoud afhankelijk van anderen. Daardoor is het voor hen vrijwel onmogelijk voor zichzelf op te komen. In dit proefschrift proberen wij deze vrouwen een stem te geven.

Hoofdstuk 1 beschrijft de redenen waarom we deze studie hebben uitgevoerd en de doelen die we ermee beoogden. Ook worden in dit hoofdstuk de methodologische en ethische overwegingen die we gemaakt hebben besproken.

In Nederland leven naar schatting tussen de 75.000 en 185.000 mensen zonder geldige verblijfsvergunning. Ongeveer een derde van deze mensen is vrouw. Deze groep vrouwen is één van de meest kwetsbare groepen in onze samenleving. Het is zeer aannemelijk dat de omstandigheden waarin zij leven van invloed zijn op hun gezondheidstoestand. Om goede zorg te kunnen verlenen aan ongedocumenteerde vrouwen is het voor artsen van groot belang weet te hebben van de algemene gezondheidstoestand van deze groep en van de relatief vaak bij hen voorkomende gezondheidsproblemen. Helaas is deze informatie niet voor handen. Onderzoeken naar de gezondheid van ongedocumenteerde vrouwen zijn schaars en richten zich alleen op de vrouwen die hun weg naar de gezondheidszorg al hebben weten te vinden. Er is geen informatie over de “onzichtbare” groep: de groep die geen contact heeft met gezondheidszorginstellingen.

In Nederland hebben ongedocumenteerde immigranten recht op alle "medisch noodzakelijke zorg". Er is echter weinig informatie beschikbaar over de daadwerkelijke toegang tot de gezondheidszorg van deze groep. Verschillende onderzoekers, gezondheidszorgwerkers en organisaties hebben hun zorg hierover uitgedrukt. Informatie over de ervaren problemen in de toegang tot de gezondheidzorg van ongedocumenteerde vrouwen zelf is echter nauwelijks voor handen. Ook bestaan er geen cijfers over het daadwerkelijk gebruik van de gezondheidszorg door ongedocumenteerde vrouwen.

Voor artsen is het leveren van kwalitatief goede zorg aan ongedocumenteerde immigranten niet eenvoudig. De zorg is arbeidsintensief. Er bestaan vaak communicatieproblemen en de gepresenteerde problematiek is vaak complex. Bovendien is er vaak geen medisch dossier van deze patiënten voorhanden, met als gevolg dat voorgeschiedenis en medicatiegebruik vaak onbekend zijn. In theorie zouden medische dossiers die mensen zelf in bewaring houden: Patientheld records (PHR's), hiervoor een oplossing kunnen zijn. Helaas bestaan er geen wetenschappelijke studies over het gebruik van dit soort dossiers door ongedocumenteerde immigranten. Het is daarom onduidelijk of een dergelijk PHR dossier ook in de praktijk goed zou kunnen werken.

Dit alles overwegende stelden wij ons met dit onderzoek ten doel:

- Het verbeteren van inzicht in de gezondheidstoestand en de specifieke somatische en psychosociale problemen van ongedocumenteerde vrouwen in Nederland.
- Het vaststellen van reproductieve gezondheidsproblemen en -behoeftes van ongedocumenteerde vrouwen en de mate waarin zij deze behoeftes kunnen vervullen.
- Het verkrijgen van inzicht in het gebruik van de gezondheidszorg door ongedocumenteerde vrouwen en het in kaart brengen van de barrières die hun gebruik van de gezondheidszorg hinderen.

- Het beoordelen van de geschiktheid van een "Patient-held record" (PHR) voor ongedocumenteerde immigranten.

Onderzoek onder ongedocumenteerde vrouwen levert methodologische problemen op, zeker wanneer daarbij ook ongedocumenteerde vrouwen betrokken worden die geen contacten hebben met gezondheidszorginstellingen of vrijwilligersorganisaties. Ongedocumenteerde vrouwen worden niet systematisch geregistreerd en daardoor is het onmogelijk om een representatieve steekproef te trekken. Om ongedocumenteerde vrouwen zonder contact met gezondheidszorginstellingen of vrijwilligersorganisaties te kunnen includeren zijn ongebruikelijke manieren van werven noodzakelijk. Daardoor is de werving van mogelijke deelnemers zeer tijdrovend en moeilijk. Daarnaast vragen het winnen en houden van het vertrouwen van de vrouwen en het garanderen van hun veiligheid grote aandacht.
We besloten een exploratieve studie uit te voeren onder 100 ongedocumenteerde vrouwen van 18 jaar of ouder, met zoveel mogelijk variatie in achtergrond kenmerken. De steekproef werd doelgericht samengesteld. De ongedocumenteerde vrouwen werden geworven met medewerking van kerken, vrijwilligersorganisaties, steunorganisaties, huisartsen en verloskundigen. Om ook vrouwen te vinden die geen contact hadden met deze personen en/of organisaties, plaatsten wij advertenties in locale kranten en hingen wij posters op op plaatsen waarvan wij wisten dat er veel ongedocumenteerde immigranten kwamen. Bovendien maakten wij gebruik van de sneeuwbalmethode: wij vroegen vrouwen die deelnamen aan ons onderzoek of zij nog andere vrouwen kenden die mogelijk zouden willen deelnemen aan ons onderzoek. De interviews werden gehouden op verschillende plaatsen: een bejaardentehuis, verschillende GGD'en, huisartspraktijken en een opvanghuis. Deze locaties werden geheim gehouden, ook voor de tussenpersonen via wie het contact met de vrouwen gelegd was. Om een genuanceerde en goede indruk te kunnen

krijgen van de gezondheid en gezondheidsproblemen van ongedocumenteerde vrouwen, de barrières die zij ervaren als zij hulp willen zoeken voor hun gezondheidsproblemen en de geschiktheid van een PHR, kozen wij ervoor verschillende methoden toe te passen: gestructureerde vragenlijsten, semi-gestructureerde interviews en focusgroep discussies. Zowel de ongedocumenteerde vrouwen zelf als hun huisartsen werden geïnterviewd. De vrouwen die deelnamen aan het onderzoek kregen een PHR uitgereikt waarin medische en persoonlijke gegevens werden vermeld. De medische gegevens werden verkregen door middel van een medische anamnese en een beperkt lichamelijk onderzoek. Als vrouwen nog geen vaste huisarts hadden, hielp de onderzoek assistente hen om er één te vinden.

In **Hoofdstuk 2** wordt informatie gegeven over de aantallen, achtergrond en leefomstandigheden van ongedocumenteerde immigranten. Ook wordt in dit hoofdstuk informatie over mensenrechten en de regelgeving betreffende de toegang tot de gezondheidszorg in verschillende westerse landen verstrekt. Verder beschrijft dit hoofdstuk demografische kenmerken en de resultaten van het lichamelijk onderzoek van onze onderzoeksgroep.

Helaas bestaat er geen correcte en algemeen geaccepteerde naam voor mensen die zonder verblijfsvergunning in een land leven. De term “illegaal” wordt vaak bekritiseerd. Wij hebben ervoor gekozen om de term “ongedocumenteerd” te gebruiken, ondanks de nadelen die ook aan deze term kleven, omdat deze term het meest breed geaccepteerd is in Europa.

Naar schatting zijn er ongeveer 30 miljoen ongedocumenteerde immigranten in de wereld. In de Verenigde Staten schat men dat 4% van de totale populatie ongedocumenteerd is. De schattingen voor Europa zijn lager: 1-2 % van de totale populatie. De demografische achtergrond van ongedocumenteerde immigranten verschilt tussen de diverse landen. In Nederland leven relatief veel ongedocumenteerde immigranten die afkomstig zijn uit Suriname, Turkije en Marokko. De redenen om zonder geldige verblijfspapieren in een land te

verblijven verschillen ook en kunnen economisch, persoonlijk of politiek zijn. In Nederland bestaat de grootste groep ongedocumenteerde immigranten uit arbeidsmigranten. Deze mensen zijn naar Nederland gekomen om economische redenen. Zij wonen voornamelijk in de vier grote steden. Veel vrouwen in deze groep zijn slachtoffer van mensenhandel en werken in de seks industrie. Ook zijn er veel vrouwen onder hen die als huishoudelijke hulp of kinderoppas werken. Verder bestaat een belangrijke groep ongedocumenteerde vrouwen in Nederland uit vluchtelingen. Onder hen zijn veel vrouwen, vaak met kinderen, die een traumatisch verleden hebben. Vaak hebben zij weinig sociale contacten. Een derde groep ongedocumenteerde vrouwen is om persoonlijke redenen zoals gezinshereniging en huwelijk naar Nederland gekomen.

De leefomstandigheden van ongedocumenteerde vrouwen zijn zorgwekkend. Zij hebben lage of wisselende inkomsten, worden vaak geconfronteerd met corrupte huiseigenaren en komen niet in aanmerking voor sociale huurwoningen. Daardoor zijn hun woonomstandigheden vaak slecht: veel mensen in kleine kamers, slecht sanitair, slechte hygiëne en afwezigheid van warm water en verwarming. Ook hun arbeidsomstandigheden laten vaak te wensen over: lage lonen, lange werkdagen, uitbuiting en onveilige situaties. Bovendien zijn of waren deze vrouwen vaak slachtoffer van fysiek of seksueel geweld. Al deze omstandigheden kunnen belangrijke gevolgen hebben voor hun gezondheids-toestand. Helaas zijn er geen onderzoeksresultaten bekend over de specifieke gezondheidsproblemen van deze groep.

Het recht op gezondheidszorg is een mensenrecht dat verankerd is in het verdrag van de Verenigde Naties over Economische, Sociale en Culturele rechten. Op grond van dit verdrag verplichten landen zichzelf om alle inwoners, dus ook mensen zonder verblijfsvergunning, adequate gezondheidszorg te bieden. Helaas blijkt in de praktijk dat adequate toegang tot gezondheidszorg voor ongedocu-menteerde immigranten niet altijd is gegarandeerd. De situatie verschilt behoorlijk tussen de diverse landen.

In **hoofdstuk 3** beschrijven we de gezondheidstoestand en de gezondheidsproblemen van onze onderzoeksgroep. De gezondheidstoestand werd beoordeeld door middel van de zelf ervaren gezondheid. Aan alle respondenten werd gevraagd een inschatting te geven van de eigen gezondheid op een 5 puntsschaal: "Beoordeelt u uw gezondheid als uitstekend, zeer goed, goed, matig of slecht." Gezondheidsproblemen werden in kaart gebracht met de open vraag: "Welke gezondheidsproblemen hebt u op dit moment?" maar ook door middel van gerapporteerde klachten op een lijst van veel voorkomende gezondheidsklachten en chronische ziekten.

We concluderen in dit hoofdstuk dat de gezondheidstoestand van deze vrouwen aandacht behoeft. Vijf en zestig procent van de geïnterviewde vrouwen beoordeelt hun eigen gezondheid als matig of slecht en 91% heeft één of meer problemen met hun gezondheid. Gemiddeld zeggen vrouwen 11 gezondheids-klachten van een lijst met 26 veel voorkomende klachten te hebben. Gynaecologische en psychische klachten komen erg veel voor, maar worden zelden spontaan gemeld. Wij concluderen dat ongedocumenteerde vrouwen belangrijke symptomen vaak niet spontaan melden als ze bij een dokter komen. (Huis)artsen dienen zich dit te realiseren en dienen actief te vragen naar psychische en gynaecologische symptomen. Speciale aandacht zou er uit moeten gaan naar zwangere ongedocumenteerde vrouwen omdat hun gezondheids-toestand hen extra kwetsbaar maakt.

We doen in dit hoofdstuk de aanbeveling om een speciale training te ontwikkelen voor artsen over de (aanpak van) gezondheidsproblemen van ongedocumenteerde vrouwen.

In **hoofdstuk 4** onderzoeken we in hoeverre ongedocumenteerde vrouwen zeggenschap hebben over hun reproductieve en seksuele gezondheid aan de hand van gegevens over seksueel geweld, gebruik van anticonceptie en abortus. Ook worden de reproductieve gezondheidsproblemen die vrouwen rapporteerden op een gestructureerde vragenlijst, beschreven in dit hoofdstuk.

We concluderen in dit hoofdstuk dat de reproductieve gezondheid van deze ongedocumenteerde vrouwen zorgwekkend is. Uit onze resultaten blijkt dat vrouwen te laat starten met zwangerschapscontroles of deze in het geheel niet krijgen. Ze gebruiken weinig anticonceptie, ondergaan relatief vaak een abortus provocatus en hebben heel vaak nooit een uitstrijkje of SOA screening gehad. Verder bestaan er bij hen veel onbehandelde seksuele en gynaecologische problemen. Ongedocumenteerde vrouwen in Nederland lijken onvoldoende zeggenschap over hun eigen seksuele en reproductieve gezondheid te hebben. Dit heeft een aantal oorzaken. Op de eerste plaats zijn zij onvoldoende geïnformeerd over de (reproductieve) gezondheidszorg in Nederland. Ook hebben zij weinig kennis over anticonceptie. Verder ervaren zij vaak problemen met de financiering van de reproductieve zorg, zijn zij vaak slachtoffer van seksueel geweld en zijn zij bang voor uitzetting. Ongedocumenteerde vrouwen in Nederland kunnen vaak niet zelf bepalen of, wanneer en hoe vaak ze zwanger worden. Deze vrouwen moeten worden "empowered" om dit wel zelf te bepalen. Ze hebben hiervoor informatie en onderwijs nodig maar ook hun persoonlijke (communicatie) vaardigheden dienen versterkt worden. Er is verder onderzoek nodig om te bepalen hoe "empowerment" bereikt kan worden in deze groep.

In **hoofdstuk 5** beschrijven we de toegang tot instellingen waar Tuberculose (TB) kan worden gediagnosticeerd en behandeld. De International Union Against Tuberculosis and Lung Disease stelde onlangs dat in alle landen laagdrempelige voorzieningen voor ongedocumenteerde immigranten zouden moeten bestaan waar TB kan worden gediagnosticeerd en behandeld zonder angst om aangegeven te worden bij de politie. We constateren dat dit niet voldoende gegarandeerd is in Nederland. Slechts 33% van de ongedocumenteerde vrouwen die in Nederland verblijven om economische of persoonlijke redenen zijn tenminste eenmaal gescreend op TB. Verschillende vrouwen met voor TB verdachte symptomen melden problemen in de toegang

tot de zorg. Wij doen in dit hoofdstuk de aanbeveling om te onderzoeken hoe TB screening aangeboden kan worden aan ongedocumenteerde immigranten en hoe bij hen het besef van de risico's van TB kan worden vergroot.

In **hoofdstuk 6** wordt het gebruik van gezondheidszorgvoorzieningen en de barrières die ongedocumenteerde vrouwen ervaren bij het zoeken naar gezondheidszorg beschreven. Wij gebruikten hiervoor zowel vragenlijsten als semi-gestructureerde interviews.

Uit de resultaten blijkt dat ongedocumenteerde vrouwen weinig gebruik maken van de gezondheidszorg in Nederland. Velen van hen hebben gezondheidsproblemen waarvoor ze (nog) geen zorg hebben ontvangen: 69% van hen meldt barrières bij het zoeken naar en/of krijgen van zorg voor hun problemen.

Het gebruik van gezondheidszorg door ongedocumenteerde vrouwen is lager dan dat van legale immigranten vrouwen en vrouwelijke asielzoekers in Nederland. Dit geldt vooral voor vrouwen die naar Nederland gekomen zijn om persoonlijke of economische redenen. Ongedocumenteerde vrouwen die naar Nederland kwamen om politieke redenen (afgewezen asielzoekers) maken meer gebruik van de gezondheidszorg dan de andere groepen. Dit valt gedeeltelijk te verklaren door het feit dat zij beter geïnformeerd zijn over het Nederlandse gezondheidszorg systeem. Gedurende hun verblijf in de asielzoekerscentra hadden zij recht op reguliere gezondheidszorg en ontvingen zij informatie over het systeem. Een andere verklaring is dat zij meer contacten met vrijwilligersorganisaties hebben dan de andere groepen. Deze organisaties spelen een belangrijke rol in het begeleiden van ongedocumenteerde immigranten naar de gezondheidszorg. Vrijwel alle vrouwen in ons onderzoek die een eigen huisarts hadden, vonden deze met hulp van een vrijwilligersorganisatie.

Veel ongedocumenteerde vrouwen besluiten geen hulp te zoeken voor hun gezondheidsproblemen vanwege persoonlijke barrières zoals schaamte, angst en

gebrek aan informatie. Deze vrouwen dienen te worden opgespoord en geïnformeerd over hun rechten, het Nederlandse gezondheidszorg systeem en het beroepsgeheim van Nederlandse artsen. Ook gezondheidswerkers moeten beter geïnformeerd worden over de bestaande regelgeving rondom ongedocumenteerde immigranten. Tevens moet hen duidelijk gemaakt worden dat zij verplicht zijn om zorg te verlenen aan deze groep. Tenslotte moet ook aandacht worden besteed aan institutionele barrières in ziekenhuizen en andere instellingen omdat deze de eerder genoemde barrières om hulp te zoeken versterken.

Hoofdstuk 7 beschrijft de resultaten van een systematische literatuurstudie naar de geschiktheid van een medisch dossier in eigen beheer, een "Patient-held Record" (PHR) voor ongedocumenteerde immigranten. Wij vonden geen enkele studie over ongedocumenteerde immigranten en PHR's. Daarom besloten we te zoeken naar het gebruik van PHR's in andere patiënten groepen. Wij vonden 61 artikelen; 42 artikelen voldeden echter niet aan onze inclusie criteria. Uiteindelijk screenden we 16 artikelen op methodologische kwaliteit. Zeven artikelen voldeden aan de criteria. In deze studies is het gebruik en de waardering van de PHR's acceptabel. Het gaat in deze studies om kankerpatiënten, psychiatrische patiënten en diabetespatiënten. De resultaten zijn bemoedigend maar niet direct toepasbaar op ongedocumenteerde patiënten. We besloten daarom een pilot studie uit te voeren naar het gebruik en de waardering van PHR's bij ongedocumenteerde patiënten.

Hoofdstuk 8 beschrijft het gebruik en de waardering van een PHR voor ongedocumenteerde vrouwen. De vrouwen in onze studie werden voorzien van een PHR. Na 3-4 maanden kregen zij een gestructureerde vragenlijst voorgelegd over het gebruik van het PHR en werd gekeken of er nieuwe aantekeningen in het PHR stonden. Tegelijkertijd kregen de huisartsen van deze vrouwen een vragenlijst toegestuurd. De meningen over het PHR werden onderzocht in focusgroepen.

Het gebruik van PHR's door ongedocumenteerde vrouwen en hun huisartsen is laag. Minder dan de helft van de vrouwen liet het PHR zien aan de huisarts. Als vrouwen geen vaste huisarts hadden, gebruikten ze het PHR vaker, maar nog steeds was het gebruik teleurstellend. Als vrouwen een vaste huisarts hadden vonden zowel de vrouwen als de huisartsen het PHR overbodig. Angst om de huisarts te belasten en/of te ergeren was een andere belangrijke reden om het PHR niet te gebruiken. Deze angst lijkt reëel. Huisartsen vrezen een toename aan administratie door het PHR en benadrukken dat het hen aan tijd ontbreekt om het boekje bij te houden. We concluderen dat een landelijke invoering van PHR's voor ongedocumenteerde immigranten niet is aan te bevelen.

In **hoofdstuk 9** worden de belangrijkste bevindingen besproken en brengen we deze bevindingen met elkaar in verband. Verder worden implicaties en aanbevelingen besproken.

Het hebben van een ongedocumenteerde status in Nederland is een ziekmakende factor voor vrouwen. Het is belangrijk deze groep als een groep met specifieke risico's te benaderen. Ongedocumenteerde vrouwen rapporteren een groot aantal gezondheidsproblemen. Deze problemen worden niet allemaal spontaan gemeld. Vooral seksuele en gynaecologische problemen worden vaak verzwegen. Dit gebeurt vooral als vrouwen in het gezelschap van hun partner of familieleden zijn. (Huis) artsen dienen daarom actief te informeren naar seksuele, gynaecologische en psychische problemen als ze deze vrouwen op hun spreekuur krijgen.

Het gebruik van de gezondheidszorg onder ongedocumenteerde vrouwen is laag. De toegang tot de gezondheidzorg is voor hen wisselend en onvoorspelbaar. De toegang is afhankelijk van de goodwill van de gezondheidswerker die ze ontmoeten. De barrières die deze vrouwen ondervinden hebben veel te maken met hun positie in de samenleving. Angst voor uitzetting zorgt ervoor dat zij ofwel geen hulp zoeken ofwel zeer voorzichtig zijn in het benaderen van een dokter. Negatieve ervaringen met werkgevers, overheidsinstanties, huisbazen en

andere gezondheidswerkers versterken deze omzichtigheid. Onze studie toont dat zij daar ook redenen toe hebben. Vrouwen die er uiteindelijk in slagen om toegang tot een dokter te krijgen slagen daar doorgaans in met de hulp van iemand die ze vertrouwen. Dit is vaak iemand van een vrijwilligersorganisatie maar het kan ook een vriend of familielid zijn. Om de toegang tot de gezondheidszorg te verbeteren is het belangrijk dat vrouwen contacten kunnen leggen met deze mensen. Wij zijn van mening dat deze vrijwilligersorganisaties gefaciliteerd moeten worden om te kunnen bemiddelen.

Ongedocumenteerde vrouwen hebben veel onbehandelde gezondheids-problemen. Dit kan in de eerste plaats leiden tot serieuze gezondheidsrisico's bij de vrouwen en hun ongeboren kinderen, maar het impliceert ook risico's voor de publieke gezondheid. Het gevaar van het aanzwengelen van deze discussie is dat men zich meer gaat richten op het beschermen van de autochtone populatie dan op het verbeteren van de gezondheidstoestand van ongedocumenteerde vrouwen. Ons onderzoek laat echter zien dat het wegnemen van barrières in de toegang van de gezondheidszorg een positief effect zou kunnen hebben op bijvoorbeeld de TB bestrijding en zodoende zowel ten goede komt aan de gezondheid van ongedocumenteerde vrouwen als aan de publieke gezondheid.

Voor de start van de studie hadden wij de hypothese dat de implementatie van PHR's voor ongedocumenteerde vrouwen een goede manier zou zijn om hen te empoweren, de toegang tot de gezondheidszorg te vergemakkelijken en de continuïteit van zorg te verbeteren. Helaas blijkt het PHR hier niet geschikt voor. Wij bedachten een oplossing voor een theoretisch probleem in de praktijkvoering, niet voor een probleem dat door ongedocumenteerde vrouwen en/of huisartsen in de dagelijkse praktijk wordt ervaren. Dit is een belangrijke valkuil bij het bedenken van interventies voor kwetsbare groepen in de samenleving die maar moeizaam voor zichzelf opkomen. Om de gezondheid en de toegang tot de gezondheidszorg te verbeteren voor ongedocumenteerde

vrouwen zal men allereerst uit moeten gaan van de problemen die ze zelf ervaren. Ook oplossingen zouden idealiter van de vrouwen zelf moeten komen.
Dit is een explorerende studie onder 100 selectief gekozen vrouwen. Men dient daarom voorzichtig zijn met getalsmatige conclusies. Toch zijn wij van mening dat deze studie belangrijke nieuwe informatie heeft opgeleverd. Er is, waarschijnlijk in verband met praktische problemen, tot nog toe erg weinig onderzoek verricht onder ongedocumenteerde vrouwen zelf. Dit is de eerste Europese studie waarin ook ongedocumenteerde vrouwen opgenomen zijn die geen contact met (gezondheidszorg) instellingen hebben. Ons doel om deze "onzichtbare" vrouwen te includeren in onze studie, is echter maar ten dele gelukt. Het bleek erg moeilijk om slachtoffers van vrouwenhandel, ongedocumenteerde arbeidsmigranten en ongedocumenteerde familieleden van legale migranten te vinden. Er is een groep ongedocumenteerde vrouwen die nog steeds "onzichtbaar" is en waar we heel erg weinig informatie over hebben. Het is aannemelijk dat hun toegang tot gezondheidszorg nog sterker beperkt is.
Hoewel ongedocumenteerde vrouwen theoretisch recht op gezondheidszorg hebben in Nederland is die toegang in praktijk onvoldoende gegarandeerd. Het verkrijgen van medische zorg voor deze vrouwen is wisselend, onvoorspelbaar en sterk afhankelijk van de attitude van de gezondheidswerker en diens wil om de bestaande regelgeving te volgen. Ongedocumenteerde vrouwen kunnen en zullen bij misstanden niet in opstand komen. Daardoor is het gemakkelijk om hun problemen te negeren. Ongedocumenteerde vrouwen bestaan niet in officiële statistieken; ze tellen niet mee in de morbiditeit- en mortaliteitscijfers. Hun gezondheidsproblemen zijn net zo verborgen als zijzelf. De Nederlandse samenleving is verantwoordelijk voor het garanderen van adequate gezondheidszorg voor deze groep vrouwen. Beleidsmakers als gezondheids-werkers dienen daarom deze "Hiding and Seeking" vrouwen op te sporen en hun gezondheidsproblemen aan te pakken.

APPENDICES

Appendix 1: information about the study for undocumented women

Geen verblijfsvergunning en toch medische hulp nodig?

Waar gaat u naartoe als u ziek bent?

Alle mensen in Nederland hebben recht op goede medische zorg, ook als zij geen verblijfsvergunning hebben. Maar mensen zonder verblijfsvergunning zoals u, kunnen geen verzekering afsluiten tegen ziektekosten. Hierdoor kan het moeilijker zijn om medische zorg te krijgen of medicijnen te kopen.
Om ook voor mensen zonder verblijfspapieren goede medische zorg mogelijk te maken, is het voor dokters belangrijk te weten welke ziektes en problemen u heeft.
Dit gaat dokter Schoevers van de afdeling vrouwenstudies van het Universitair Medisch Centrum St Radboud onderzoeken. Daarvoor heeft zij uw hulp nodig! Want alleen u kunt vertellen hoe het is om zonder verblijfsvergunning te leven.
Als u mee doet, krijgt u eerst een gesprek met de assistente van het onderzoek mevrouw Straver. Zij vraagt aan u wat u doet als u ziek bent, en of u problemen heeft met het vinden van een dokter. Ook zal zij u alles vertellen wat u wilt weten over de Nederlandse gezondheidszorg. Hierna bespreekt de dokter, mevrouw Schoevers, met u welke ziektes u heeft en welke medicijnen u gebruikt. De dokter zal ook naar uw hart en longen luisteren. Zij schrijft uw gegevens op in een boekje, uw medisch dossier. Dat boekje is daarna van u. U kunt dat voortaan altijd meenemen als u naar een dokter gaat. Dat is handig omdat dan elke dokter kan zien welke ziektes u heeft gehad en wat andere dokters eraan gedaan hebben. U bepaalt zelf wat er in het dossier wordt opgenomen. Er hoeft dus niks in te staan wat u liever niet wilt. Want er is altijd een klein risico dat andere mensen (uw familie of huisgenoten) uw dossier lezen.

Als u nog geen eigen huisarts hebt, zoeken wij die voor u.

Het onderzoek duurt in totaal ongeveer 2 uur. Als u wilt is er een tolk bij.

Ongeveer drie maanden hierna vragen wij u nog een keer hoe het gaat, en of u uw medisch dossier gebruikt hebt.

Vergoeding

Als u meedoet aan het onderzoek, krijgt u een cadeaubon van 15 euro.

GEHEIM Alleen mevrouw Straver en dokter Schoevers weten uw naam. Niemand anders hoort wie meedoen aan het onderzoek. Uw adres hoeven ook zij niet te weten.

Meer informatie?

Bel dan mevrouw Straver : 024-3619049.

We hopen dat u met ons onderzoek mee wilt doen,

Dokter Schoevers, onderzoekster.

Ons onderzoek is goedgekeurd door de Commissie Mensgebonden Onderzoek van het Universitair Medisch Centrum Sint Radboud. Deze commissie houdt er toezicht op dat deelnemers aan onderzoek geen schade oplopen door het onderzoek en heeft daarvoor het onderzoek verzekerd tegen aansprakelijkheid. Bij dit toezicht hoort ook, dat er een onafhankelijke dokter is, die zelf niet met dit onderzoek mee doet en er dus geen belang bij heeft .Bij deze dokter kunt u terecht als u klachten hebt over het onderzoek, die u niet met ons wilt bespreken. Deze dokter krijgt uw naam alleen te horen als u hem zelf belt. Dit is Dokter W. van den Bosch Tel: 024 – 3616328 (dinsdag en donderdag)

Als u mee wilt doen, wilt u dan uw voornaam en telefoonnummer hieronder opschrijven en dit papier opsturen in de enveloppe die hier bij zit. Er hoeft geen postzegel op.

Ja, ik wil meedoen aan het onderzoek naar de medische zorg voor vrouwen zonder verblijfspapieren.

Mijn (voor)naam is:……..

Mijn telefoonnummer is:……

Handtekening:……

Appendix 1a: Information about the study in Russian

ниверситетский Медицинский Центр

Нет вида на жительство, но всё же необходима медицинская помощь?

К кому обратиться, если вы заболели?

Всё население Нидерландов имеет право на соответствующее медицинское обслуживание, даже в случае если нет вида на жительство. Но лица без вида на жительство, как вы, не могут оформить медицинскую страховку. Поэтому им может быть трудно получить медицинскую помощь или приобрести лекарства.

О тех, у кого нет необходимого вида на жительство, нам важно иметь инфомацию о состоянии их здоровья. Мы хотим знать, какие у вас болезни и проблемы, и что вы делате в случае, если вам нужен врач и лекарства.

Этим будет заниматься домашний врач Марианна Схруверс из отделения обследования женщин при университетском Медицинском Центре им. Св.Радбауд. Для этого ей нужна ваша помощь! Так как только вы можете рассказать о том, как можно жить без вида на жительство. Мы хотили бы вам задать несколько вопросов о вашем здоровье и о том, что вы делаете, если вы заболели: как вы находите домашнего врача и как попадаете в больницу. Эту беседу проводит ассистентка г-жа Мархрит Стравер, и длится она приблизительно 1 час. У нас есть возможность зарезервировать для вас переводчика.

Г-жа Стравер также может рассказать вам всё о системе здравоохранения в Нидерландах, если вы захотите об этом знать.

После этой беседы уже домашний врач г-жа Схруверс обсудит с вами ваши медицинские жалобы: какие у вас есть заболевания и какие лекарства вам необходимы. Она занесёт ваши данные в специальную книжку, в ваше медицинское досье. После этого эта книжка ваша, вы её можете всегда брать с собой, если идёте к врачу. Домашний врач даст вам также советы о том, при каких жалобах к какому врачу лучше обратиться. В случае, если у вас нет своего домашнего врача, мы для вас его найдём.

Приблизительно через 3 месяца мы вас снова вызовем, чтобы узнать, использовали ли вы ваше медицинское досье.

Вознаграждение! Если вы принимаете участие в этом исследовании, то получаете подарочный талон на 15 €.

Тайна! Только г-жа Мархрит Стравер и домашний врач Марианна Схруверс будут знать ваше имя и место вашего проживания. Никто другой не будет знать, что вы принимали участие в этом исследовании.

Больше информации ?

Звоните г-же Стравер : 024-3619049.

Мы надеемся, что вы примите участие в нашем исследовании,

Доктор Марианна Схруверс, исследователь.

Appendix 2: Medical interview by GP

PROTOCOL MEDISCH ONDERZOEK:

Datum:

Registratienummer vrouw: NIJ

Tolk:

Ja/nee m/v

1. Uitleg van verdere gang van zaken.

De vrouw beslist zelf wat er in het medisch dossier wordt vermeld.

2. Gezondheidsklachten

3. Anamnese:

Heeft u een van de volgende chronische ziekten:

Diabetes	Ja/nee	?
Astma/ COPP	Ja/nee	?
Hartziekten	Ja/nee	?
Hoge bloeddruk	Ja/nee	?
Bloedarmoede	Ja/nee	?
Kanker	Ja/nee	?
Beroerte, hersenbloeding of herseninfarct	Ja/nee	?
Epilepsie	Ja/nee	?

Overige nl:

4. Indien bekend met een chronische ziekte: worden deze ziekten gecontroleerd? Ja/nee

Zo ja, door wie?

- specialist
- huisarts
- alternatieve genezer
- ander

5. Bent u wel eens geopereerd? Ja/nee

Zo ja, waarvoor?

Waar en wanneer?

6. Bent u wel eens opgenomen in een ziekenhuis? Ja/nee ?

Zo ja, waarvoor?

Waar en wanneer?

7. Heeft u een van de volgende infectieziekten (gehad)?

Hepatitis	Ja/nee	Ooit getest	Ja/nee	?	Resultaat:	ziekte+/ziekte-/?
HIV	Ja/nee	Ooit getest	Ja/nee	?	Resultaat:	ziekte+/ziekte-/?
Malaria	Ja/nee/?					
Worminfecties	Ja/nee/?					
Meningitis	Ja/nee/?					
SOA's	Ja/nee	Ooit getest	Ja/nee	?	Resultaat:	ziekte+/ziekte-/?
Bilharzia:	Ja/nee/?					
Tuberculose	Ja/nee/?					

8. Bent u voor tuberculose gecontroleerd in Nederland? Ja/nee ?

Wanneer?

Welk resultaat? Ziekte+/ziekte-/?

9. Draagt u een bril? Ja/nee

10. Bent u de laatste jaren regelmatig naar een tandarts geweest? Ja/nee

11. Rookt u? Ja/nee

Zo ja, hoeveel sigaretten per dag:

12. Drinkt u alcohol? Ja/nee

Zo ja, hoeveel glazen per dag:

13. Gebruikt u drugs? Ja/nee

Welke –marihuana

- cocaïne
- heroïne
- XTC
- overig

14. Heeft u het laatste jaar meer dan twee seksuele partners gehad? Ja/nee

15. Heeft u zich het laatste jaar voor seks laten betalen? Ja/nee

Was dat een beslissing van uzelf of is er iemand die je daartoe
Dwingt?

16. Bent u ergens allergisch voor? Ja/nee

17. Bent u ooit zwanger geweest? Ja/nee
Zo ja, waar, wanneer, termijn, geboortegewicht en uitkomst

18. Waren er problemen rondom de bevalling bij de vorige zwangerschappen? Ja/nee
Zo ja, welke problemen?

19. Bent u op dit moment zwanger? Ja/nee
Zo ja wordt de zwangerschap gecontroleerd door een verloskundige? Ja/nee
Zo ja, heeft u een advocaat Ja/nee

Weet uw advocaat dat u zwanger bent? Ja/nee

20. Bent u in Nederland zwanger geweest (zonder papieren) Ja/nee

21. Werd de zwangerschap gecontroleerd? Ja/nee

Zo ja vanaf hoeveel weken?

- Eerste trimester
- Tweede trimester
- Laatste gedeelte
- > 38 weken

Zo ja door wie?

- verloskundige
- huisarts
- gynaecoloog
- overig

22. Waar bent u bevallen?

- thuis
- ziekenhuis
- overig tw:

23. Heeft u kraamzorg gehad? Ja/nee

Zo ja, hoe ging dat?

24. Hebt u ooit een abortus ondergaan? Ja/nee

Zo ja, waar en wanneer?

25. Gebruikt u een voorbehoedsmiddel Ja/nee

Zo ja welk?

- pil
- prikpil
- mirenaspiraal
- gewone spiraal
- spiraal onbekend type
- condoom
- sterilisatie
- overig

Zo nee, zou u een voorbehoedsmiddel willen gebruiken? Ja/nee

26. Hebt u ooit voorlichting gehad over voorbehoedsmiddelen? Ja/nee

Zo ja, wanneer, waar en van wie?

27. Bent u ooit mishandeld? Ja/nee

28. Bent u ooit seksueel misbruikt? Ja/nee

Wilt u daar iets over vertellen?

29. Heeft u de laatste tijd wel een last van de onderstaande klachten?

1. (onder)buikpijn	Ja/nee
2. Vaginale afscheiding?	Ja/nee
3. Vaginale jeuk?	Ja/nee
4. Menstruatiestoornissen, onregelmatig bloedverlies?	Ja/nee
5. Moeite om plas op te houden? Andere plasklachten?	Ja/nee
6. Vruchtbaarheidsproblemen? (indien partner)	Ja/nee
7. Problemen/pijn bij seksueel contact	Ja/nee

30.Heeft u de afgelopen maand last gehad van de volgende klachten:

1.Vermoeidheid	Ja/ nee
2.Gewichtsverlies	Ja/nee, zo ja: hoeveel kg
3.Hoesten	Ja/nee
4.Bloed ophoesten	Ja/nee
5.Hartkloppingen	Ja/nee
6.Benauwdheid/ ademhalingsproblemen?	Ja/nee
7. Beklemd gevoel/ pijn op de borst	Ja/nee
8.Buikpijn	Ja/nee
9.Hoofdpijn	Ja/nee
10.Duizeligheid	Ja/nee
11.Rugklachten	Ja/nee
12.Huid – en haarproblemen	Ja/nee
13.Slecht zien	Ja/nee
14.Slecht horen	Ja/nee
15.Gebitsproblemen	Ja/nee
16.Slaapproblemen	Ja/nee
17.Nachtmerries	Ja/nee
18.Lusteloosheid, nergens zin in hebben	Ja/nee
19.Angstig, zenuwachtig zijn	Ja/nee
20.Snel geïrriteerd zijn	Ja/nee

Appendix 3: selection of pages of patient-held record

MEDISCHE VOORGESCHIEDENIS

CHRONISCHE ZIEKTEN:

Diabetes: **sinds:**

Hypertensie: **sinds:**

Epilepsie: **sinds:**

Hartziekte: **sinds:**

Astma/COPD: **sinds:**

Andere ziekten: **sinds:**

BELANGRIJKE OPERATIES:

Jaar	Plaats	Operatie

OVERIGE MEDISCHE VOORGESCHIEDENIS:

Jaar	**Plaats**	

ALLERGISCH VOOR:

MEDICATIE:

Naam Medicijn	*DOSERING*	**start**

Appendix 4: Information folder

ALS U ZIEK BENT EN GEEN PAPIEREN HEBT……

Kunt u in Nederland wel hulp van een dokter en medicijnen krijgen!

Hoe vind ik een dokter?

In Nederland ga je niet meteen naar het ziekenhuis maar eerst naar de **HUISARTS.**

Adressen en telefoonnummers van huisartsen staan in het telefoonboek. U kunt ook vrienden of familie vragen of ze een huisarts kennen. In Nederland heeft iedereen een eigen huisarts. Het kan moeilijk zijn om een vaste huisarts te vinden. Veel huisartsenpraktijken zijn vol.

Wat doet een huisarts?

Een huisarts is een arts die minstens 9 jaar heeft gestudeerd. Meestal draagt hij/zij gewone kleren dus geen witte jas. De huisarts zal u onderzoeken en als het nodig is medicijnen voorschrijven of advies geven.

Als de huisarts u zelf niet kan helpen kan hij/zij u verwijzen naar het ziekenhuis. De huisarts schrijft dan een brief voor de arts in het ziekenhuis. Deze brief moet u meenemen naar het ziekenhuis.

Hoe krijg ik de huisarts te zien?

Bij de meeste huisartsen moet je een **afspraak** maken. Dit kunt u doen aan de balie of via de telefoon. In Nederland is het belangrijk op tijd te komen op uw afspraak. Als u te laat bent moet u vaak weer een nieuwe afspraak maken.

Als u een afspraak heeft, heeft de huisarts meestal **10 minuten** tijd voor u. De meeste huisartsen spreken **Engels en Duits.** Eventueel kan de huisarts een tolk voor u bellen. De huisarts werkt meestal van maandag tot en met vrijdag van 08.00 tot 17.00. 's avonds, 's nachts en in het weekend kunt u alleen in spoedgevallen een huisarts zien. Meestal moet u dan naar een speciale **huisartsenpost.**

Hoe krijg ik medicijnen?

Medicijnen voor uw hart of voor suikerziekte of antibiotica bijvoorbeeld kunt u niet zelf kopen. Voor deze medicijnen hebt u een **recept** nodig. De huisarts kan u zo'n recept geven. De medicijnen kunt u dan ophalen bij de apotheek.

Pijnstillers en medicijnen voor kleine kwalen zoals maagzuur kunt u wel zelf kopen. Dat kunt u doen in de apotheek maar ook in de drogist.

Krijg ik altijd medicijnen als ik naar de huisarts ga?

In Nederland geven dokters alleen medicijnen als u het echt nodig hebt. Nederlandse dokters geven niet vaak antibiotica. Ook andere medicijnen geven ze niet zo vaak. Dat is misschien anders dan u gewend bent.

Kan ik die huisarts vertrouwen?

Nederlandse huisartsen hebben een **beroepsgeheim.** De huisarts mag aan **niemand** vertellen welke ziektes en problemen u hebt. De huisarts mag ook uw adres niet aan anderen geven, dus ook niet aan uw familie, man, broer. De huisarts heeft geen contacten met de politie of de IND.

Wat moet ik doen in een spoedgeval?

Als u heel erg ziek bent en niet meer zelf naar de huisarts toe kunt gaan moet u dat zeggen. De huisarts kan dan bij u thuis langskomen. Dat heet een **visite.** Een visite is wel veel **duurder** dan een gewone afspraak. Probeer daarom als het kan gewoon naar de praktijk te komen.

Als uw leven in gevaar is kunt u (of iemand anders) **112 bellen.** Dit mag alleen in heel ernstige gevallen. Vaak komt er dan een **ambulance** om u naar het ziekenhuis te brengen.

Wat doe ik als ik kiespijn heb?

Als u kiespijn hebt hoeft u niet naar de huisarts te gaan. U kunt **direct** naar de **TANDARTS.** Ook tandartsen kunt u in het telefoonboek vinden. Bij de tandarts moet u eerst een afspraak maken. De tandarts zal meestal de tand of kies trekken. Andere behandelingen moet u zelf betalen.

En wat als ik zwanger ben?

Dan maakt u een afspraak met een **Verloskundige.** Als u **3 maanden** zwanger bent wil de verloskundige u graag voor het eerst zien. Ook namen en adressen van verloskundigen vind u in het telefoonboek.

Kunnen mijn kinderen hier ook vaccinaties krijgen?

Ja, uw kinderen kunnen dezelfde vaccinaties krijgen als Nederlandse kinderen. De vaccinaties zijn gratis. De vaccinaties worden gegeven op het **consultatiebureau.** Daar worden baby's en kleuters ook regelmatig onderzocht. Ze worden er gewogen en gemeten. U kunt er ook adviezen krijgen. Ook dit is gratis. U kunt een afspraak maken via de GGD.

Hoe gaat het met betalen?

De huisarts, de verloskundige en de tandarts zullen u vertellen hoeveel u moet betalen. Soms sturen ze een rekening. Als u niet (alles) kunt betalen vertelt u dat aan de huisarts of de assistente. Ook als u de medicijnen niet kunt betalen vertelt u dat uw huisarts.

Als u de rekening niet kunt betalen kan de huisarts geld terug krijgen van een speciaal fonds.

Ook van het ziekenhuis zult u een rekening krijgen. Leg ook daar uit waarom u niet (alles) kunt betalen.

Wat kan ik doen als een dokter me niet wil helpen?

Niet alle huisartsen, tandartsen, verloskundigen en ziekenhuizen weten wat ze moeten doen met mensen zonder papieren die ziek zijn. Soms denken ze dat ze mensen zonder papieren niet mogen helpen. Ook weten ze vaak niet dat ze geld terug kunnen krijgen als u niet kunt betalen. **Uw dokter kan altijd bellen met de *helpdesk Lampion* telefoonnummer: 030 2349855.** Ook u kunt altijd bellen met Lampion bij problemen.

ZELF INVULLEN:

BELANGRIJKE ADRESSEN EN TELEFOONNUMMERS:

NAAM HUISARTS :
ADRES :
TELEFOONNUMMER:

HUISARTSENPOST :

BIJ LEVENSGEVAAR : **112**

CONSULTATIEBUREAU :
NAAM TANDARTS :
TELEFOONNUMMER:
NAAM VERLOSKUNDIGE :
ADRES :
TELEFOONNUMMER:
NAAM APOTHEEK :
ADRES :
TELEFOONNUMMER:

Appendix 5: Follow-up interview with research assistant

EVALUATIE MEDISCH DOCUMENT VROUWEN

Naam:

Datum:

Nummer:

DEEL A: INTERVIEW

1. Hebt u uw medisch dossier nog in uw bezit? Ja/nee

2. Zo nee, wat is er mee gebeurd?

3. Bent u na ons onderzoek nog bij de huisarts geweest? Ja/nee
   Zo nee, verder naar vraag 12

4. Zo ja, hoe vaak?

5. Waarvoor?

6. Heeft u ook uw medisch dossier meegenomen? Ja/nee

7. Zo nee, waarom niet? (ga verder naar vraag 12)

8. Zo ja, heeft u het aan de dokter gegeven? Ja/nee

9. Zo nee, waarom niet?

10. Zo ja, heeft de dokter er ook iets ingeschreven? Ja/nee

11. Zo nee, waarom niet?

12. Bent u na ons onderzoek nog bij andere hulpverleners geweest?
Ja/nee

13. Heeft u hen uw medisch dossier gegeven? Ja/nee

14. Zo nee, waarom niet?

15. Zo ja, heeft de hulpverlener iets geschreven? Ja/nee

16. Zo nee, waarom niet?

17. Hebt u gedaan wat in het medisch advies werd geadviseerd? Ja/nee

18. Zo ja, hoe ging dat?

19. Zo nee, waarom niet?

20. Wat vind u van het medisch dossier?

21. Gaat u het medisch dossier in de toekomst gebruiken? Ja/nee/?

22. Zo ja, in welke situaties?

23. Zo nee, waarom niet?

24. Waar bewaart u het medische dossier?

25. Heeft u het medisch dossier aan iemand laten zien? Ja/nee

26. Zo ja, aan wie?

27. Zo nee, waarom niet?

28. Bent u bang dat iemand er in zal kijken? Ja/nee

29. Heeft iemand anders er wel eens in gelezen? Ja/nee/?

30. Hoe vond u dat?

DEEL B: INSPECTIE DOSSIER

Inspectie medisch dossier mogelijk Ja/nee

Indien inspectie niet mogelijk:

Reden:

Indien inspectie mogelijk:

Staat van het boekje Goed/ matig/slecht

Nieuwe notities Ja/nee

Zo ja welke:

Van wie:

Appendix 6: Results of physical examination and screening percentages

Table 1: Abnormal findings in physical examination

	Total study pop. N=100
Weight:	
Underweight (BMI < 18,5)	3%
Mild overweight (BMI 25-29)	9%
Obesitas (BMI > 30)	17%[1]
Blood Pressure	
Slightly high (140/90 – 180/100)	19%
Severely high (> 180/100)	6%
Anemia	
Mild anemia (Hb 6 – 7,5 mmol/l)	37% (N=89)
Severe anemia (Hb <6)	9%[2]
Severe caries / dental problems	37%
Other abnormalities physical examination	33%
Use of medication	60%
Advice for further action to GP	20%

1. Prevalence of underweight in legal non-western migrant women in the Netherlands is 3%
   Prevalence of overweight in legal non-western migrant women in the Netherlands is approx.30%
   Prevalence of obesitas in legal non-western migrant women in the Netherlands is 15-25%
   (Dagevos H, Dagevos J: Minderheden meer gewicht: over overgewicht bij Turken, Marokkanen, Surinamers en Antillianen en het belang van integratiefactoren , DEN Haag: Sociaal en Cultureel Planbureau, 2008.)
2. Prevalence of anemia in women in the Netherlands 3%
   (Van Wijk MAM, Mel M, Muller PA, Silverentand WGJ, Pijnenborg L, Kolnaar BGM. Huisarts Wet 2003;46(1):21-9.Standaard anemie)

   Prevalence in migrant women in the UK is much higher: 20% (Fischbacher C, Bhopal R, Patel S, White M, Unwin N, Alberti KGMM. Anemia in Chinese, South Asian, and European populations in Newcastle upon Tyne: cross sectional study. BMJ 2001;322:958-9)
3. No blood sample was taken in 11 women either because it was recently taken or because they refused.

Table2: Screening and prevention in different groups of undocumented women

	Total study pop. N=100	Political reasons N=59	Non political reasons N =41
TB screening	70%	95% (56)	34% (14)
HIV test	29%	15% (9)	45% (19)
STD check	20%	12% (7)	32% (13)
Mammography Screening[1] (N=19)	32% [2](6 of 19)	43% (6 of 14)	0% (0 of 5)
Influenza vaccination (N= 13)[3]	46% (6 of 13)[4]	45% (5 of 11)	50% (1of 2)

1. Women 50-75 years as this group is invited to join the national breast cancer screening program in the Netherlands;
2. Participation rate of non-western migrant women to the Dutch screening program for breast cancer is 63%. Vermeer, Bertine, Van den Muijsenbergh, Maria E. The attendance of migrant women at national breast cancer screening in the Netherlands 1997 – 2008. European Journal of Cancer Prevention: 2010; 19 :195-198
3. Women with an indication because of chronic disease or age above 65
4. Participation rate of non-western migrants to the influenza vaccination is 82%

Dankwoord

In de tijd dat ik als huisarts werkte in het asielzoekerscentrum in Wijchen, verdwenen er regelmatig mensen "met onbekende bestemming". Dat gebeurde vaak vlak voor hun (vermeende) uitzetdatum. Wij wisten dat ze waarschijnlijk in de illegaliteit verdwenen. Soms verdwenen ze zonder aankondiging vooraf, zonder dat ik bijvoorbeeld nog een voorraad aan medicatie had kunnen regelen. Zo was een 8 maanden zwangere vrouw uit Guinee met ernstige PTSS klachten en hoge bloeddruk plotseling weg. Ik heb nooit meer wat van haar gehoord. Je maakt je dan ernstige zorgen over een dergelijke patiënt, maar ze is onbereikbaar, onvindbaar. Je kunt alleen maar hopen dat ze de juiste mensen tegen zal komen.

Toen mij ter ore kwam dat Maria van den Muijsenbergh en Toine Lagro onderzoek wilden doen naar toegang en gezondheidstoestand ongedocumenteerde vrouwen was ik direct geïnteresseerd en blij met de kans die me geboden werd. Ik hoopte dat het onderzoek vragen zou kunnen beantwoorden en oplossingen zou kunnen aandragen voor deze kwetsbare en zo moeilijk bereikbare groep.

Het was niet altijd gemakkelijk het traject dat aan de totstandkoming van dit boekje voorafging. Er waren veel onverwachte hindernissen die we soms creatief konden oplossen maar soms ook moesten accepteren en slikken. Ervaringen overigens die ongedocumenteerde vrouwen dagelijks meemaken. Toch was het voor mij ondanks alles een positieve periode en dat komt zeker ook door de steun en hulp die ik van zoveel verschillende mensen heb gehad. Op deze plaats wil ik een aantal mensen in het bijzonder bedanken.

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Margriet Straver, wandelende verjaardagskalender, steun en toeverlaat, wat fijn dat we samen de interviews konden doen! Samen op stap met de rode bus. Wat hebben we een bijzondere tijd gehad. Wat was het soms zwaar, emotioneel, beklemmend, angstig, frustrerend……Maar wat hebben we ook vaak gelachen en wat hebben we veel hartverwarmende, sterke en bijzondere mensen ontmoet. Maar wat ben jij ook een bijzonder mens! Dank je voor al je steun.

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Op verscheidene plekken hebben wij op een zeer prettige manier de interviews kunnen afnemen en/of de focusgroep gesprekken kunnen organiseren. Op de achtste verdieping van verzorgingstehuis Nijevelt in Nijmegen, bij de GGD hart van Brabant in Den Bosch, bij de vrouwenopvang in Rosmalen, de GGD Rotterdam-Rijnmond, de huisartspraktijk van Sylvie Lo Fo Wong en Hans Harmsen in Rotterdam, huisartspraktijk Vaillantplein in Den Haag, huisarts-praktijk Lepelaarssingel Rotterdam, het kantoor van Dokters van de Wereld in Amsterdam, verloskundigen praktijk Maashaven in Rotterdam en het kantoor van de "Commission for Filippino Migrant Workers" in Amsterdam. Alle medewerkers van deze instellingen bedankt voor jullie gastvrijheid, belangstelling, medewerking en voor de talloze kopjes koffie.

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"Aggoe", mijn vader, ik wil je bedanken voor je tomeloze inzet om mijn spreektaal Engels om te buigen in schrijftaal Engels en voor al het andere. De "Merriam- Webster" is na 5 jaar tijd vrijwel versleten. Misschien is het nu toch tijd om met pensioen te gaan?

Mam, jou wil ik bedanken voor al die speciale attente dingen van jou die het leven weer een stuk leuker en gemakkelijker maken en voor je onvoorwaardelijke steun.

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Curriculum Vitae

Marianne Schoevers werd geboren op 27 juli 1962 in Amersfoort en groeide op in Drachten, 's Hertogenbosch, St. Michielsgestel en Venray. In 1980 deed ze eindexamen Atheneum B aan de scholengemeenschap Jerusalem te Venray.

Na het behalen van haar propedeuse rechtsgeleerdheid begon zij in 1981 met de studie Geneeskunde aan de Katholieke Universiteit Nijmegen. Na haar afstuderen in 1988 werkte zij anderhalf jaar als arts-assistent Chirurgie en als arts assistent Interne Geneeskunde in ziekenhuis de Lichtenberg te Amersfoort. Van 1990- 1992 volgde zij de tweejarige beroepsopleiding tot huisarts, wederom in Nijmegen. Van 1992 tot 1994 was zij werkzaam als waarnemend huisarts in de regio Groningen en later als huisarts in de asielzoekerscentra Zuidlaren en Geeuwenbrug. Daarna volgde zij de Nederlandse Tropencursus voor Artsen (NTA) bij het KIT in Amsterdam.

In april 2005 vertrok zij met haar gezin naar Malawi. Daar werkte zij als Medical Supervisor op de Out Patiënt and Casualty Department van het universiteitsziekenhuis Queen Elizabeth Central Hospital in Blantyre. Naast de zorg voor deze zeer grote en drukke afdeling was zij betrokken bij het onderwijs aan medisch studenten en Clinical Officers. Ook werd hier haar interesse voor wetenschappelijk onderzoek gewekt. Zij deed er onder andere onderzoek naar de invloed van traditional healers op de behandeling van epilepsie.

In 1999 keerde zij terug naar Nederland waarna zij tot juni 2000 als waarnemend huisarts in de regio Arnhem werkte. Vervolgens was zij in 2000 en 2001 huisarts in OC Ede en het KOC in Arnhem. Na haar verhuizing naar Mook werkte zij als HIDHA in gezondheidscentrum de Hazenkamp in Nijmegen en als huisarts in AZC Wijchen. Ook schreef zij enkele kinderboeken.

Na de sluiting van AZC Wijchen was ze als onderzoeker verbonden aan de afdeling Eerstelijnsgeneeskunde van de Radboud Universiteit Nijmegen bij

Vrouwenstudies Medische Wetenschappen van 2005 tot september 2010. Het laatste jaar werkte zij op deze afdeling tevens als docent in het basiscurriculum Geneeskunde in het onderwijs rondom het coschap huisartsgeneeskunde (CKO7).

Inmiddels is zij gestart met een herintredingtraject als huisarts bij de VOHA in Nijmegen.

Marianne is getrouwd met Martin Boeree en samen hebben zij 2 kinderen: Suzanne (1995) en Stijn (1996).